

# FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador with President Bolsonaro of Brazil (left) and Health Minister Mandetta (right) during a live Facebook broadcast on July 8.

**MESSAGE**

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## Back to Brazil

Brazil is the only country yet to reach the WHO's goal of eliminating leprosy as a public health problem, defined as a prevalence rate of less than 1 case per 10,000 population. Recently I made my first trip to the country in four years because political circumstances in the intervening period had not lent themselves to a visit.

I was discussing the leprosy situation with President Bolsonaro when he suggested: "Let's address the people directly." He pulled out his smartphone and said live on Facebook: "Let's eliminate leprosy from our country!" He also gave me, the health minister and the human rights minister an opportunity to speak.

The response was tremendous. In two days, the broadcast had been viewed 500,000 times and subsequently 730,000 times. Facebook became a new tool for raising leprosy awareness.

In my activities I not only offer encouragement to health officials and undertake plenty of radio and TV work, I also attach great importance to responding to listeners and viewers.

In Brazil I appeared on three TV programs and

five radio shows and felt the keen interest there was in leprosy. Going forward, I would like to focus on having a nation's top leaders carry out awareness-raising via Facebook, TV and radio as a way to reach out to the maximum number of people.

During my stay, I sensed a new sense of purpose. Health Minister Mandetta has treated leprosy patients in the past and pledged to actively engage in the issue.

Governor Dino of Maranhao state announced he wanted to reduce patient numbers by 90 percent in three years. Meanwhile, the federal government has agreed to hold a national conference on leprosy by March next year.

Under President Bolsonaro's strong leadership, I believe the efforts of Health Minister Mandetta and others involved will lead not only to the elimination of leprosy but also to zero leprosy one day. I promised to make any number of visits to the country and am proud to work alongside Brazilian friends and colleagues in these efforts.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Harmful Stereotypes

UN expert focuses on challenges for women and children in latest report.

Wrongful stereotyping and structural violence against women and children affected by leprosy were the focus of the latest report by the UN expert on leprosy presented at the 41st session of the Human Rights Council in Geneva in June.

In her report, Dr. Alice Cruz, the UN special rapporteur on elimination of discrimination against persons affected by leprosy and their family members, said, “The overlapping of harmful stereotypes, wrongful stereotyping and structural iniquities strengthens exclusion, discrimination and violence on the grounds of leprosy and compromises the enjoyment of fundamental rights, such as dignity, equality and non-discrimination, by millions of persons affected by leprosy worldwide, as well as by many of their family members.”\*

**The figure of 8% of new cases of leprosy accounted for by children under 15 “is shamefully high.”**

Harmful stereotypes about leprosy can lead to informal segregation and widespread exclusion by treating individuals as untouchable; segregating individuals within the household and also prohibiting them from leaving the house.

They can also result in divorce on the grounds of leprosy and prohibiting marriage with an affected person or any of his/her family members; barring individuals from participating in religious and community activities as well as in economic transactions; dismissing individuals from their jobs; pushing individuals into begging; and banishing individuals from the community.

## THE CHALLENGE FOR WOMEN

According to the report, women are at a higher risk of developing leprosy-related physical impairments and disability. Some of the institutional barriers to diagnosis and prevention of physical impairments in women result from institutional factors, including: discriminatory legal frames; under-financing of healthcare and poorly implemented policies for prevention, care and rehabilitation; the status of leprosy services integration into primary care; the reach of health services; and the gender of the health-care workforce in primary care services.

But social barriers also prevent women from accessing health care, such as harmful traditional beliefs and practices; the low status assigned to women, which is at the root of women’s widespread self-concealment of the disease; dependency of women on third-party authorization in order to

access health services; women’s limited mobility; illiteracy; and poor knowledge of leprosy.

## SITUATION OF CHILDREN

About 8% of the total of new cases reported by 150 countries to WHO in 2017 were children under 15 years of age, “a shamefully high figure,” according to Cruz.

Enduring under-detection of new cases of leprosy in children and late diagnosis are causal factors of physical and psychosocial impairments and disabilities. Physical impairments can worsen over time without proper care requiring follow-up studies, “the absence of which hinders a clear understanding of the real conditions faced by children affected by leprosy in the medium and long term,” the report said.

Treatment dropout rates in children range from 10% to 20% in some national programs, the main cause being the child’s refusal to cooperate in swallowing tablets and the long duration of the treatment.

However, no paediatric formulations are on the horizon, given the overall lack of funds for leprosy. Cruz also noted reports of attempted suicide among adults who were diagnosed with leprosy in childhood and who experienced multilayered stigmatization from a very early age.

## RECOMMENDATIONS

The special rapporteur recommends general and specific measures that states, national human rights institutions and civil society organizations can take in order to implement a human rights-based approach to resolving the issues that women and children affected by leprosy face.

Among them are:

- inclusion of women affected by leprosy in national plans for gender equality, gender violence prevention and empowering women through measures that can ensure economic independence and women’s access to justice;
- research into the risk factors that may perpetuate violence against children affected by leprosy, alongside the formation of integrated partnerships of experts, parents, teachers and young people that can respond effectively to such violence;
- ensuring children with leprosy-related disabilities participation on an equal basis with others in education services, recreational, leisure and sporting activities; and
- systematically approaching, consulting and involving persons affected by leprosy and their representative organizations in decision-making processes that directly affect their lives, with the guarantee of all measures for ensuring the participation of women and children and all persons with leprosy-related disabilities. ■



A fact sheet summarizing the report.

## FOOTNOTES

\* In compiling the report, Cruz undertook an online and individual consultation with persons affected by leprosy, their family members, health workers and NGO personnel, and received a total of 575 responses from eight high-burden countries—Brazil, Ethiopia, India, Indonesia, Nepal, Myanmar, Nigeria and the Philippines—and 16 others.

# Telling It Like It Is

Global Forum aiming to provide ‘people’s perspective’ on leprosy issues.



Manila here we come: the regional assembly in Rio was the last before the Global Forum that takes place this September in the Philippines

A Global Forum of people’s organizations on Hansen’s disease will bring together representatives from organizations of persons affected by Hansen’s disease from 20 countries, together with major stakeholders as observers, for four days of exchanges from September 7 to 10 ahead of the 20th International Leprosy Congress in Manila, Philippines.

Hansen’s disease, also known as leprosy, is a curable infectious disease treated with multidrug therapy (MDT) available free of charge worldwide. Since the introduction of MDT in the early 1980s, some 16 million persons have been treated and cured, while annual new case numbers have plateaued at around 200,000 in recent years.

Regardless of the progress made, challenges remain to breaking transmission of the disease and further reducing case numbers to achieve the goal of “zero leprosy”. Meanwhile, persons diagnosed with Hansen’s disease and their family members continue to face stigma and discrimination, which acts as a barrier to early case detection and treatment, limits their opportunities in life, and leads to social and economic exclusion.

## STRUGGLE FOR INCLUSIVE SOCIETY

Over the years, organizations of persons affected by Hansen’s disease have formed that are actively engaged in the struggle for an inclusive society, free from discrimination and prejudice. Both The Nippon Foundation and Sasakawa Health Foundation have been supporting a number of these organizations for

more than 20 years in some cases.

But while the active participation and wider involvement of people’s organizations in policy making and in medical and social programs is seen as crucial to making further progress against Hansen’s disease, people’s organizations face a number of challenges in common, including a lack of organizational sustainability and capacity to enable them to achieve their long-term goals.

## DISCUSSING WHAT MATTERS

The purpose of the Global Forum is to discuss these and other issues important to people’s organizations and provide delegates to the 20th International Leprosy Congress with a “people’s perspective” on Hansen’s disease issues to help sharpen efforts against the disease by all stakeholders going forward.

Around 100 participants are expected to take part—60 representatives from people’s organizations from 20 countries, 30 major stakeholders as observers and 10 resource persons.

There will be workshops on Social Business/ Fundraising/Management and on Networks & Volunteers, and sessions on Human Rights, Sustainability and Public Health. The Goodwill Ambassador is due to address delegates on September 9.

The Global Forum aims to enhance the ability of people’s organizations to make their voices heard, strengthen ties between people’s organizations and stakeholders, create a regional/global alliance of people’s organizations and promote a joint campaign for World Leprosy Day 2020.

The results of the four days of discussions will be shared at the opening ceremony of the 20th International Leprosy Congress on September 11 and there will also be a session the same day for further discussion.

The Global Forum is being sponsored by the Office of the Joint Program of Hansen’s Disease (Leprosy) of The Nippon Foundation and Sasakawa Health Foundation, which also sponsored three regional assemblies of people’s organizations held earlier in the year in Africa (Addis Ababa, Ethiopia), Asia (Manila, Philippines) and Latin America/ Caribbean (Rio de Janeiro, Brazil). ■



Scenes from the three regional assemblies of people’s organizations held earlier this year: (left to right) Addis Ababa, Manila and Rio de Janeiro.

# In Praise of Abrahão Rotberg

Half a century ago, a Brazilian dermatologist began using the term Hansen's disease.

I first 'discovered' Hansen's disease almost 30 years ago. I have since gone on to study and research it from many aspects—epidemiological, clinical, paleopathological, historical and more. I have been in contact with persons affected by Hansen's disease in Brazil, in the U.K. and in France. Nevertheless, I have always been troubled by the feeling that physicians and researchers, despite all our efforts, could be doing more for patients and their family members.

Around 80 years ago, many Brazilian physicians recommended isolating patients and separating them from their healthy children, policies that violated human rights and contributed to increasing the stigma of the disease. Since then, steps have been taken to address the consequences of these past policies in the form of compensation and other measures.

While there are still many issues to be resolved, there is one action that Brazil has taken that I think would make a significant contribution to improving the quality of life of persons affected by the disease if adopted throughout the world—changing the name of the disease.

In Brazil, we use the term Hansen's disease, not leprosy. The Hebrew term *tsara'ath*, translated as "leprosy" in the Bible, probably referred to a number of different cutaneous manifestations of diseases, including but not limited to Hansen's disease.

In addition to being medically imprecise, the term was loaded with wider meaning. In the Bible, it is used as a metaphor for defilement, and this has saddled it with negative connotations ever since. Unfortunately, when Dr. Hansen identified the disease-causing bacillus in 1873, he labeled it *Mycobacterium leprae*, thus yoking it to this negative history.

Beliefs stemming from the Bible that leprosy is synonymous with uncleanness, decay, corruption and filth are still very much present in countries where Hansen's disease exists and even in those where cases are few and far between. Among health professionals, too, there are individuals who display discriminatory attitudes toward leprosy, and these attitudes can be communicated to patients, their families and the wider community.



Health poster for Hansen's disease: "Identified. Treated. Cured."

## NO PLACE FOR 'LEPROSY'

Abrahão Rotberg was born in Rio de Janeiro, Brazil in 1912. A dermatologist and hansenologist, he attended medical school in Sao Paulo and would later head up the state of Sao Paulo's then-Department of Prophylaxis of Leprosy. Rotberg was against the policy of isolating patients in place at the time and as department head he suspended the policy. He also renamed the department the Department of Sanitary Dermatology.

He was fiercely opposed to the term leprosy and the "millenary load" of superstition that it carried. No amount of educating people about "leprosy" could erase the stigma attached to the word, he believed. Instead, he argued for the use of a new term, "hanseníase" (Hansen's disease), sending letters to colleagues around the world and promoting it at medical conferences.

He fiercely opposed the term leprosy and the "millenary load" of superstition that it carried.

In 1970, he succeeded in getting the Sao Paulo state health department to abolish leprosy from its official terminology, while continuing to push for the term Hansen's disease to be introduced more widely.

In 1974, during the 10th International Leprosy Congress in Bergen, Rotberg obtained many signatures for a petition to change the name of leprosy to Hansen's disease; however, very few colleagues followed up on the initiative.

In 1975, he published an article denouncing the continued use of the term leprosy, saying that the word was being retained by some NGOs to help them raise funds at the cost of perpetuating stigma and discrimination against those affected by the disease.

That same year, his efforts were rewarded with a presidential decree that officially changed the name of leprosy to Hansen's disease in Brazil. However, it wasn't until 1995 that this decree became a federal law that banished the term leprosy and its derivatives from official documents.

Thanks to the efforts of Rotberg, physicians in Brazil no longer learn about leprosy, but Hansen's disease, and patients are no longer diagnosed with a biblical affliction. I believe that the name change may well have been the most effective action Brazil has taken to reduce stigma and combat discrimination.

Considering that one of the three pillars of the WHO's Global Leprosy Strategy 2016-2020 is "Stop discrimination and promote inclusion," how about the rest of the world adopting the term Hansen's disease, just as Rotberg once dreamed? ■



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# Window on a Closed World

New portal site makes Fontilles accessible to researchers as never before.

In 1909, eight persons affected by leprosy living in desperate circumstances were taken to a newly built hospital in the wooded hills above Valencia on the east coast of Spain. This was the beginning of the Sanatorium Francisco de Borja, the initiative of a local lawyer and a Jesuit priest to care for those with the disease.

In the more than 100 years since its founding, the sanatorium commonly known as Fontilles has dedicated itself to both the medical and social needs of persons affected by leprosy. In the process, it has become a repository of history—a history that is now accessible as never before thanks to a new online portal.

“Fontilles and Leprosy in Spain” is a collaboration between the Fontilles Foundation and the University of Alicante, with funding provided by Sasakawa Health Foundation to organize, classify, store, and digitize materials. These include medical files, photos, letters, maps, research reports, as well as a large number of book and journals.

Over the years, Fontilles has been home to over 2,600 persons affected by leprosy. Separated from the outside world by a wall, they formed a community with its own rich heritage and institutions—a church, a theatre, a bar, hairdresser, bakery and more.

Fontilles also became a center for research with its own laboratory and Spanish-language scientific

journal. Today less than two dozen long-term residents remain, but Fontilles continues to discharge its duty of care to them while serving as a referral and training center for leprosy.

“The buildings, the wall, the fields and the landscape of the Fontilles valley are a physical testimony of these lives, of the personal and collective histories that they defined and, also, of a still unknown part of the social, political, medical and cultural history of Spain, as are thousands of documents, books and magazines, photographs and posters,” the University of Alicante’s Antonio Garcia Belmar writes. “The portal ‘Fontilles and Leprosy in Spain’ aims to be an open window to that closed world.”

Visit the portal at the Miguel de Cervantes Virtual Library of the University of Alicante:

[http://www.cervantesvirtual.com/portales/fontilles\\_y\\_la\\_lepra\\_en\\_espana/](http://www.cervantesvirtual.com/portales/fontilles_y_la_lepra_en_espana/)



Miguel de Cervantes

## BOOK

### VOICES FROM NIGERIA

“Arguably, one of the most egregious of deprivations and injustices suffered by persons affected by leprosy over the years has been the lack of opportunity to tell their own stories in their own words.” So states the introduction to a new book that represents a welcome step to correct this omission.

*A Question of Justice: Persons affected by Leprosy in Eastern Nigeria tell their own stories in their own words* is a compilation of accounts of those who have encountered leprosy—as patients, as relatives of patients and as health workers—in the now defunct Eastern region of Nigeria.

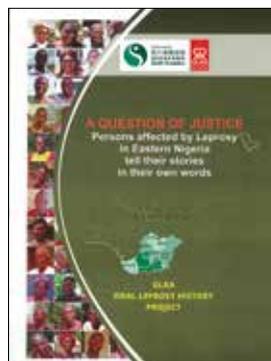
The 188-page book, published by the German Leprosy and TB Relief Association with support from Sasakawa Health Foundation, features the testimonies of 35 men and 17 women whose experiences span a period from 1945 to 2019.

They include Donatus Onwe, who recalled: “I was married before leprosy struck. But immediately I was diagnosed with this disease, she ran away.” Or Mrs. Adiah Christina, who said: “They don’t care to know if I am alive or dead, they don’t even want

to know if I am still suffering from the disease.”

There are stories of rejection and betrayal, of lost opportunities and broken marriages—all because of leprosy. But also expressions of gratitude—to God, to health workers—for how life has turned out. As Matthias Onyema writes, “I think leprosy opened more doors for me than if I had not had the disease. I come from a very warped family background and I believe God saved me from a kind of destitution that would have enveloped me if I was without leprosy.”

The book includes a Foreword by Dr. John Manton, associate professor in history at the London School of Hygiene and Tropical Medicine, who trained the team that conducted the interviews. Nigeria, he notes, “has been central in the global history of leprosy,” and research carried out in the country, and the role of Nigerian patients in “seeking and agreeing to treatment, allowing their bodies to be observed, reporting on their experiences with a wide variety compounds, did a huge amount to make modern therapy not only successful, but possible.” Fitting, then, that their stories can now be heard.



# A Rewarding Visit to Brazil

The Goodwill Ambassador travels to Brazil for the first time in four years and together with the president a makes a live broadcast to the nation to raise awareness of leprosy.

## BRAZIL (June 30-July 10)

As I was leaving Brazil at the end of my recent visit, an airport worker stopped me and said, "I saw you on Facebook." He was referring to the live Facebook broadcast I participated in with President Jair Bolsonaro when I had called on the president a couple of days earlier.

The president and I had been talking about Hansen's disease when he took his phone from his pocket and suggested that we address the nation via his Facebook page. Needless to say, I had no objection.

"Hansen's disease is a disease found around the world. Brazil has the second highest number of cases. Our country is fighting to eliminate Hansen's disease. It is essential that everyone passes on correct information about the disease to those around them," the president said.



Looking on as the president broadcasts to the world via Facebook

As Goodwill Ambassador, I have always made a point of seeking political commitment from the top for leprosy control. A word from a leader can have enormous impact. I have also made a point of going through the media to raise awareness of leprosy, and have given countless interviews to newspapers, radio and television, including on this trip to Brazil.

But this was the first time these two strands of my activities came together in a live Facebook broadcast. It happened on the spot; it reached hundreds of thousands of people instantly; and it was the president who took the initiative to make it happen.

While my meeting with the president was the most consequential of this visit to Brazil, I had many other encouraging encounters during my 10-day stay, which took me to the leprosy-endemic states of Para and Maranhão in addition to the federal capital, Brasília.

In Brasília, I called on Dr. Mandetta at the Ministry of Health. Dr. Mandetta is from Campo Grande in Matto Grosso do Sul, a state that sees many cases of the disease. An orthopedic surgeon, Dr. Mandetta told me he has been performing reconstructive surgery on patients with disabilities due to Hansen's disease for the past 30 years. In fact, both his father and his grandfather had worked at a Hansen's disease sanatorium in the state, so he has long familiarity with the disease.

I told him that I was delighted to know that someone who has worked with leprosy was in charge of the health ministry and that this would no doubt accelerate Brazil's efforts against the disease.

Heading north to Para state, I visited the Marcello Candia Hospital where I was shown around by Dr. Claudio Salgado, the president of the Brazilian Hansen's Disease Association. Built in the 1930s, the former hospital colony for Hansen's disease

**I have always made a point of seeking political commitment from the top for leprosy control.**

He also asked for comments from others who were present: Health Minister Luiz Mandetta, Human Rights Minister Damaraes Alves, Foreign Minister Ernesto Araujo and Faustino Pinto, the national coordinator of MORHAN—the Association for the Reintegration of Persons Affected by Hansen's Disease—who was sitting to the president's right.

That live broadcast went on to be viewed hundreds of thousands of times. Moreover, not only was the broadcast seen by a huge number of people, it also attracted some 18,000 comments.



Health Minister Mandetta is an orthopedic surgeon

(Right) Maria has successfully completed her treatment; (far right) receiving a warm welcome at Marcello Candida Hospital



in Marituba today serves as a referral center and rehabilitation facility.

Later in the day I met with Governor Helder Barbalho in Belem, the state capital. He explained to me the challenges to delivering health care in such a vast state, but said he was committed to seeing that people have knowledge of leprosy from an early age.

My next destination was Maraba, 500 kilometers south of Belem and Para’s third biggest city, where Mayor Sebastiao Miranda has come up with a novel initiative to promote treatment compliance in an area where people face economic hardship (see below). The municipality is one of 20 in six states that are benefitting from the Bangkok Special Fund that was set up by The Nippon Foundation after the 2013 International Leprosy Conference in Thailand to promote innovative approaches to case finding.

Situated in Brazil’s northeast, Maranhão state reports the second highest number of cases in the country. Over dinner with Governor Flavio Dino in São Luís, he told me that when he had been a parliamentary deputy, he had visited a village where around 30 of the 80 people he met had deformities that he recognized to be caused by leprosy. He vowed that if ever he became governor, he would take steps to do something about the disease.

As good as his word, he has made Hansen’s disease one of Maranhão’s priority issues. It is

actively searching for cases, taking steps to prevent disability and is running awareness programs in schools and agricultural areas. One positive side effect of placing more health teams in areas with many cases of leprosy has been a reduction in rates of maternal and child mortality. I was very taken by the governor’s efforts, and said I hoped that Maranhão could become a model case for the whole country.

While in Maranhão, I visited the Recanto Verde Basic Health Center in the municipality of San Jose de Ribmar, another which is making use of the Bangkok Fund to step up its efforts against leprosy. There I saw for myself one result of the municipality’s activities, when I met Maria. She had been diagnosed by a doctor at the health center and had just received the good news that she had completed her treatment.

I also visited Aquiles Lisboa Hospital in São Luís, where I spoke to a mother who had brought her son to be examined for leprosy after her suspicions were aroused by a patch on his skin. She knew the symptoms because she had seen a health poster.

Familiarize yourself with leprosy is a message I always hammer home in my media work. This time was no different in the radio and TV interviews I gave during my stay. I feel sure, however, that on this occasion it was my live broadcast with President Bolsonaro that had the biggest impact. ■

**FOOD FOR THOUGHT**

The mayor of Maraba has come up with a novel way to encourage treatment compliance—by offering a basket of basic foodstuffs to patients as an incentive to complete their course of multidrug therapy (MDT).

At the time of my visit to the municipality in Brazil’s Para state, 172 patients were registered to receive provisions worth 150 Real (about US\$40) per person, on the condition that they do not stop taking their MDT.

According to Mayor Sebastiao Miranda, many patients are from low-income families and are spread throughout the municipality, including rural areas.

While leprosy is not an easy disease to catch, it is a fact that it is more likely to occur in those living in poverty with

poor levels of hygiene and nutrition. At the same time, those on low incomes can find it harder to comply with treatment if it means they have to take time off work or travel long distances to reach the nearest health center.

Thus I applaud the efforts of Mayor Miranda to provide an incentive to people to come forward for treatment and see it through to the end. I heard that the bill passed through the legislature very quickly, because assemblymen understood the importance of assisting people living in a situation of social vulnerability.

At a commemorative ceremony to enact the ordinance, I thanked Mayor Miranda and his colleagues for the initiative, which I described as a humanitarian gesture that truly had the



Mayor Miranda’s ordinance: a humanitarian gesture

needs of patients in mind. I can’t think of another example like this.

“This ordinance will remain in place even after my term ends,” the mayor told me. “I want to eliminate Hansen’s disease from Maraba.”

# Face-to-Face Apology

Japanese prime minister meets with patients' kin, promises to provide compensation.

Japanese Prime Minister Shinzo Abe has met with family members of persons affected by Hansen's disease and apologized for the stigma and discrimination they suffered, following the government's decision not to appeal a court ruling awarding them compensation.

"On behalf of the government, I offer a heartfelt apology," Abe said at the meeting at the prime minister's office in Tokyo on July 24, bowing before more than 40 family members whose relatives had been forcibly quarantined in the past under Japan's Leprosy Prevention Law.

On June 28, the Kumamoto District Court in southwestern Japan ordered the state to pay a total of 376 million yen (around \$3.47 million) in damages to 541 out of 561 plaintiffs for the discrimination they had endured, and the severing of family ties, as result of the government's past policies on Hansen's disease. It ruled that the state had acted illegally by failing to end segregation of patients by 1960, despite medical advances, and retaining the Leprosy Prevention Law until 1996, which fostered discrimination not just against patients but their families as well.

In the meeting, which the plaintiffs had sought, Abe said: "Those of you here today have also been subjected to extremely harsh prejudice and discrimination against Hansen's disease; that is a



Source: Official Website of the Prime Minister

grim and undeniably fact. Consequently, you have been obliged to endure tremendous suffering and hardships over the course of a truly long period of your precious lives."

He said that the government would introduce new legislation to compensate family members of former Hansen's disease patients, including those who did not participate in the lawsuit, and work toward eradicating discrimination and prejudice.

"It is a great step forward," Chikara Hayashi, who led the plaintiffs in the damages suit, told a press conference after the meeting. Said another of the plaintiffs, Harumi Oku, 72, "I shed tears when I realized we had finally gotten to meet the prime minister." ■

## INFOLEP

Look out for exciting changes to the Infolep leprosy information services portal, coming soon. In 2018, the portal was used by 21,893 people from 185 countries and offers access to 28,500 publications.

[www.leprosy-information.org](http://www.leprosy-information.org)



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## FROM THE EDITOR

### HELPING HAND

HANDA Rehabilitation and Welfare Association works in China for the social and physical rehabilitation of persons affected by leprosy and to promote social integration, based on the principles of "equality, participation, dedication and empowerment." While it has been supported over the years by grants from overseas organizations, including Sasakawa Health Foundation (SHF), it is increasingly having to develop social business in order to generate income to sustain its activities. To date, this social business has taken place within China, such as when the government purchases HANDA's services to enhance the capacity of local NGOs, based on HANDA's experience and track record.

Now, for the first time, HANDA has the opportunity to take its expertise overseas to counsel an NGO grappling with issues of organizational sustainability and capacity-building.

PerMaTa is an organization of persons affected

by leprosy in Indonesia that works to raise awareness of leprosy, encourage people to seek treatment and promote social integration. But PerMaTa faces a number of challenges and would benefit from the know-how that HANDA can offer.

Discussions are ongoing, with both HANDA and PerMaTa expressing interest in forming such a partnership during a meeting organized by SHF in Indonesia in July to talk over the possibility. In the event that the idea goes ahead, it would be funded by SHF, which would enable HANDA to offer PerMaTa consultation and mentoring.

From SHF's perspective, this would represent an innovative way to support HANDA by creating a social business opportunity rather than by offering a grant, while helping PerMaTa to strengthen its capacity to fulfill its mission of serving persons affected by leprosy in Indonesia.

It could be a win-win situation for all concerned.