WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination
OF Leprosy

August 2018 • Number 91

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

Patients under treatment for leprosy display blister packs of MDT at an awareness-raising rally in Nampula Province, Mozambique, in July.

MESSAGE

Small Island States and Leprosy

From July 20 to 23 I visited the Union of Comoros in Africa. The union consists of three islands located between Madagascar and Mozambique. The prevalence rate of leprosy is especially high on the island of Anjouan, where it is above 9 per 10,000 population, while the percentage of child cases is alarmingly high at almost 40%.

The health ministry has been taking measures through the WHO, but because the country's population is less than 1 million, it falls outside the WHO's leprosy elimination framework. One gets the sense that it has been left behind by elimination activities. The same is true of the Pacific island states of Kiribati, which I visited in 2015, as well as the Marshall Islands and the Federated States of Micronesia. In total, there are 58 small island developing states in the world with a population under 1 million, of which 38 are UN member states.

Small island states have several distinctive characteristics. First, their small physical size and population. Second, their territory tends to be scattered across the ocean. Third, surrounded by water, they are isolated and far away from major markets.

These factors raise the cost of initial interventions, which, coupled with the fact that governments do not have sufficient funds, make it difficult to allocate appropriate personnel and implement countermeasures against the disease. On top of this, leprosy's low position on the list of health priorities contributes to further delays.

However, while these factors can be regarded as constraints on leprosy control, they can also be seen as advantages. For example, the small scale of these countries means that it should be possible to have a visible impact with less support than would be required for a country with a high population and prevalence rate.

Small island states are not so highly prioritized within the WHO Global Leprosy Programme's support framework. As we wait for Brazil to pass the milestone of eliminating leprosy as a public health problem, is it not now time to consider concentrating our efforts on supporting these small island states? We must not overlook the patients in these countries confronting the disease.

— Yohei Sasakawa, WHO Goodwill Ambassador

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PUBLICATION

Tapping the Wisdom of the People

New booklet underscores key role that persons affected by leprosy have to play.

A leprosy awareness session in Bangladesh

Strengthening participation of persons affected by leprosy in leprosy services (SPP) by utilizing their valuable experiences of the disease is one of the WHO's global strategies to ensure and sustain quality leprosy services. Guidelines for strengthening participation were published by the WHO in 2012.

Of late, SPP's contribution to leprosy control has been given more attention. This is partly because leprosy has a low profile within health agendas due to the sharp decline in the number of patients over the past three decades.

As a result, the expertise found among health care personnel in leprosy services is rapidly weakening. Furthermore, multifaceted leprosy issues require many other kinds of skills and expertise in addition to health and medical, including peer support and counseling, socioeconomic empowerment, and development.

SPP is taking place in many parts of the world. However, the scale and scope differ given the diverse range of situations with regard to leprosy epidemiology, including the maturity of each group of persons affected by leprosy and the level of understanding and support of the national government.

With the aim of promoting SPP further, a handy guide has now been published, giving concrete examples of SPP activities carried out by eight organizations in seven countries. Several years in the making, *Good Practices in Strengthening Participation of Persons Affected by Leprosy in Leprosy Services* has as one of its aims to provide health care personnel and NGOs with practical information on how to initiate SPP activities. It introduces each organization, the work they do, the impact they have, the challenges they face, the support they receive and the lessons they have learned

But *Good Practices* also hopes to help persons affected by leprosy see their experience with the disease as a valuable asset—and recognize their potential to create a better society free from leprosy-related problems.

In the excerpts that follow, organizations describe in their own words some of the activities they carry out and, in doing so, communicate what SPP has to offer.

CASE FINDING

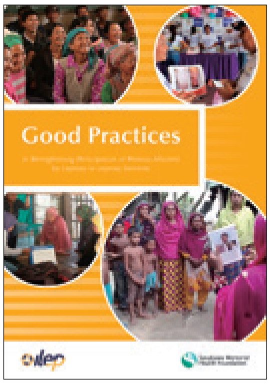
Danusha Self-Help Groups Federation, Nepal: People in the communities who want to know if a skin problem they have could be leprosy visit our self-help groups and ask us, before going to a health post. We are recognized for our leprosy work and our knowledge regarding the disease. Many of our groups have become primary referral agents for leprosy, and people seek consultation from us.

> We talk with them, motivate and assure them that…we are there to accompany them.

If we find anyone who has possible signs of leprosy or skin problems during our daily activities, at the market, or at work, we advise and encourage them to go for an examination to a health post, the district health office, or an international NGO leprosy service center. Some of us also actively visit homes to look for those with signs. Lately, as part of a new project, we are now able to identify lymphatic filariasis in addition to leprosy.

ADHERENCE TO TREATMENT

Felehansen, Colombia: We know that adherence to treatment is essential, so we contact people when they are starting multidrug therapy, to reassure and inform them about the scope of the disease and encourage them to complete their treatment. We talk with them, motivate and assure them that we, who have gone through the same experience ourselves, are there to accompany them. We inform them about the rehabilitative and economic support they can get from the government. We instruct them in how to prevent disabilities and guide them in doing self-care. We also tell them about the Federation and the benefits of being organized and united.



Good Practices is published by the International Federation of Anti-Leprosy Associations (ILEP) and Sasakawa Memorial Health Foundation, and was prepared at the request of ILEP's Temporary Experts Group on Strengthening Participation of Persons Affected by Leprosy in Leprosy Services. It can be downloaded here: www.smhf.or.jp/e/672/

Explaining about leprosy in Colombia

A self-help group meets in Nepal

COUNSELING

Bogra Federation for Leprosy and Disability Development, Bangladesh: We know that many persons affected by leprosy have low opinions of themselves; they feel less worthy than others and isolate themselves from society because of shame. Rather often they are not accepted by their families, and women affected by leprosy may be abandoned by their husbands.

We provide counseling both to our peers and to their relatives. The family needs to understand what it means to have leprosy, so that they can unreservedly accept an affected member among them. For these one-to-one talks, we visit the people in their homes.

AWARENESS-RAISING

Shashemene Leprosy Affected Persons Association, Ethiopia: We want to reach different target groups with our awareness campaigns. First of all, the general community needs to understand leprosy so that they stop stigmatizing and excluding us. We also approach sectors of the government—the labor and social affairs departments—to ensure that they have a correct understanding of leprosy and accordingly increase their commitment for support. Last but not least, our peers, people affected by leprosy and their families, are in great need of knowledge and awareness about the disease, so that they can overcome self-stigma and be accepted by their families.

We organize events to raise awareness; for example, community discussions where everybody can contribute their ideas about how to reduce stigma. We have celebrated World Leprosy Day every year since 2000. We involve religious leaders to help spread a correct message about leprosy and we directly advocate with the government for the rights of persons affected by leprosy and their families.

ACCESSING RIGHTS

Sam Uttham, India: We provide information to the communities in the colonies about services that are available to them, opportunities for education and training, support for livelihood and housing, and the provision of pensions, ration cards, and the Indian biometric identification card. We educate people about their rights and entitlements, and teach them how to apply and where to file reports. In cases of rights abuse, we collect evidence and conduct peaceful demonstrations and strikes to get the attention of the authorities involved.

SOCIOECONOMIC DEVELOPMENT

Enterprise Self-Care Group KUK, Indonesia: We began with running an "arisan," a traditional savings cycle, where each member puts in a fixed small amount of money every week, and one member is drawn to get the entire weekly savings. We did this very successfully, and then started a real savings and loan scheme. Later we added more sub-groups, for example to produce handicrafts together.

We developed the savings and loan scheme together with an external facilitator from an international NGO. We discussed and decided on clear rules, functions of group members and ethical codes, and put this all in writing. These rules and regulations are very important, and as a result, we have very good repayment rates and are able to continuously provide new loans to our members.

SERVING THE WIDER COMMUNITY

Danusha Self-Help Groups Federation, Nepal: We did not stop at improving our own situation. In our communities, almost everybody is poor and we want to contribute to our village development. To identify possible goals, our self-help groups meet with community members to discuss local issues and then seek solutions together. We have, for example, organized many adult literacy classes for illiterate women. We are active in improving sanitation, wells, roads, and housing. To successfully advocate for support, we draw on our good connections with local and district government units. In the beginning, the international NGO guided us, but today we can do most things by ourselves. ■

QUOTE

"It is very satisfying to tell a person: 'I had leprosy, too. Don't stop your treatment! You will get better!'"

AMBASSADOR'S JOURNAL

A Journey to the Comoros Islands

The Goodwill Ambassador travels to the country with the highest percentage of child cases of leprosy, and revisits Mozambique to assess the situation 10 years after it achieved the elimination of leprosy as a public health problem.

UNION OF COMOROS (July 20-23)

Located in the Indian Ocean between Mozambique and the northern tip of Madagascar, the Union of Comoros consists of three islands with a total population of around 850,000. A fourth island, Mayotte, remains under French administration after it chose not to join Grand Comoros, Anjouan and Moheli in forming an independent state in 1975.

Comoros is the only country among the 47 overseen by the WHO's Africa Regional Office (WHO AFRO) where the prevalence rate of leprosy is above 1 case per 10,000 population. It also has the highest percentage of child cases in the world, approaching 40% of new cases. This was my first visit, and I wanted to find out what was holding Comoros back.

Of the three islands, Anjouan is highly endemic for leprosy. During the French colonial period, it served as a leprosarium. Some theorize that this may have made the present-day population genetically more susceptible to the disease. But there are other factors at work, too. Anjouan is poor, densely populated and children suffer from malnutrition, all factors creating favorable conditions for transmission.

Dr. Alexander Tiendrebeogo, the WHO focal person for leprosy in Africa, added a further detail, telling me that Comoros was very late in taking up the WHO's recommended treatment regimen for leprosy using multidrug therapy (MDT). The WHO first recommended MDT in 1981, but it wasn't introduced to Comoros until 2001—20 years later.

A view of Mutsamudu, the capital of Anjouan, the most densely populated of the three islands that comprise the Union of Comoros

In the interim, a team from the Institute of Tropical Medicine, Antwerp, conducted research using a single-dose treatment for paucibacillary (PB) leprosy and a six-week course of treatment for multibacilliary (MB) leprosy cases—compared with the recommended regimen of six months' MDT for PB cases and 12 months for MB cases. By 2000, this had led to a high rate of relapses.

Having belatedly introduced the prescribed MDT regimen from 2001, Comoros achieved the leprosy elimination target of reducing prevalence to below 1 case per 10,000 population; however, it was not able to sustain this after 2007.

A closer look at the figures puts the issue in sharp relief. In 2017, Comoros recorded 429 new cases of leprosy, making for a prevalence rate of 4.58 per 10,000; this compares with 0.22 for the WHO AFRO region as a whole. The new case detection rate was 51.80 per 100,000 population, compared with 0.20 for WHO AFRO.

By island, Grand Comoros accounted for 2 cases,

FIELD OF DREAMS

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) is one of the most impressive organizations of its kind. With 70 branches around the country and some 20,000 fee-paying members, it works to eliminate discrimination and exclusion and enable persons affected by leprosy to participate fully in society.

En route to Comoros, I made a stopover in Addis Ababa, where ENAPAL's managing director Tesfaye Tadesse (photo) briefed me on its recent activities. These include an income-generation project involving the production of cooking stoves and fire guards, collaborating with schools to engage pupils in early case detection, and creating employment opportunities for children of persons affected by leprosy.

The most exciting news was that ENAPAL has received a 1,500-square-meter plot of land from the government on which to build a new headquarters. The planned four-storey building, which will serve as ENAPAL's center of operations, will include office space, accommodation and training facilities. ENAPAL intends to rent out the ground floor to commercial enterprises for income-generating purposes as it looks to find a path to sustainability and self-reliance. Work on the foundations was due to start soon after my visit.

"The new office will help us reach all over the country and beyond—we want to work without boundaries and help those in neighboring countries, too," said former ENAPAL chairwoman, Birke Nigatu. "We will be able to reach many people through this building."

(Right) Checking supplies of MDT at Hombo Hospital; (far right) posing with two siblings (to my left and right) under treatment, together with their mother and another young patient

Moheli 58 and Anjouan 369. There were 164 child cases, of which Anjouan contributed144.

While the rate of child cases is very high by WHO AFRO standards—over 38% versus 10% for the region—by contrast the rate of Grade 2 disability at time of diagnosis is only 2%, compared with around 14% for the region, indicating that cases are being diagnosed early.

My visit began on the main island, Grand Comoros, where I called on Minister of Health, Solidarity and Gender Promotion Dr. Rashid Mohamed Mbarak Fatma. The next day I traveled to Anjouan, accompanied by the health minister and other officials.

One of my first tasks was to pay a courtesy call on Governor Dr. Abdou Salami Abdou to explain my mission. I expressed concern about the high rate of child cases and requested that he use his position to speak out about leprosy so that awareness reaches every corner of society. The governor drew my attention to the fact that Anjouan is the poorest island in the union, underlining the broader context in which Anjouan's leprosy problems must be viewed. "We need to improve the condition of the people," he told me.

That afternoon I attended a meeting of government officials, partners and experts to discuss the situation on the island. It was clear that despite the efforts of the country's leprosy program, which is supported by its international partner Action Damien, there are insufficient human and material resources to cover the island in a timely fashion.

Mini case-detection campaigns have had some success over the years, but they have only taken place occasionally and reach only some of Anjouan's communities. There is also no organized effort involving persons affected by leprosy that could assist in case finding.

I visited Hombo Hospital, where the doctors, health workers and Action Damien members tackling leprosy are based. While there, I met a number of outpatients undergoing treatment with MDT. They included a girl whose symptoms had been spotted by another patient; a pair of brothers—the older of whom had identified signs of leprosy in his sibling as a result of his own experience of the

UNWAVERING OPTIMIST

I have met many people who have dedicated their life to leprosy work. I can now add 78-year-old Dr. Saverio Grillone to that list. Dr. Grillone—not a medical doctor, as he is quick to tell me—has spent the last 40 years in the Comoros islands where he now works as coordinator for Action Damien on Anjouan.

After earning a law degree and then studying for a PhD in psychology, Dr. Grillone took a course on leprosy at the Fontilles sanatorium in Spain before going to work in Ethiopia. Returning to his native Italy, he had the chance to accompany an Italian leprosy mission to Comoros in 1977, two years after the islands gained their independence from France. When the mission was withdrawn, he approached Action Damien as he wished to continue his work.

In the early days, there was a lot of discrimination and nurses did not want to be involved with leprosy patients, he told me. Dr. Grillone approached the president of the day and gained his understanding to build a leprosy section within the dermatology wing of Hombo Hospital, rather than an isolated facility elsewhere.

When the ward was completed, funded by Fondation Damien, the president declared that leprosy patients were no longer to be referred to by a stigmatizing term found in the Comorian language. "He really understood," Dr. Grillone told me. "It led to improvements in the way people with leprosy were treated by society and their families."

Less quick to improve have been the poverty, malnutrition and overcrowding that impact the program's ability to eliminate leprosy—"and there are other factors that need to be investigated, such as genetic susceptibility and the role of monkeys and ticks as possible disease vectors," he told me.

Dr. Grillone does point to some positive developments. "More cases are being discovered by patients themselves and a relationship of trust has built up with leprosy workers. Patients know that treatment is free and they won't be asked for money. Word is spreading," he said.

With Dr. Grillone (right) on Anjouan

"Over these 40 years, I have always remained an optimist and never felt that that what I am doing is hopeless, although there have been times when I've felt I haven't made a difference," said Dr. Grillone. "Your visit has given me renewed strength—and thanks to your visit, the health minister has come, too."

disease; and a girl who was diagnosed by follow-up screening after a case was found in her village.

Showing the power of the media, reports of my visit had prompted an anxious mother to bring her daughter to the hospital for a checkup, although it turned out that the blemish on the young woman's skin was not leprosy.

From the hospital, I traveled 75 minutes through lush tropical rain forest to visit a clinic in Mahale, a community of some 10,000 people in the northeast of the island. It had already seen around new 10 cases this year by the time of my visit, including a first-year university student and a 65-year-old man already disabled by the disease. Based on the figures for this one village alone, I could get a feel for the extent of the challenge on Anjouan.

Dr. Rashid, the health minister, told me that Comoros aims to reduce the country's prevalence rate to below 1 by 2030 and that her ministry is working on plans to bolster the leprosy control program. Later, when I paid a courtesy call on President Azali Assoumani, he suggested a more ambitious target of 2025 and I hope this will be pursued.

As always, I took the opportunity of press conferences on Anjouan and Grand Comoros to enlist the support of the media, telling them their role in helping to reduce the number of patients is extremely important. "By taking an interest in this issue, you can make a huge difference," I said, calling on them in their reporting to encourage families to conduct skin checks for tell-tale signs of the disease.

I left Comoros with the feeling that activities on Anjouan need to be scaled up so that every village is covered. If every health facility is adequately trained to diagnose and treat leprosy, and if people affected by leprosy and others in the community can become more involved in identifying cases and referring them to health workers, this will help to increase the detection rate.

Comoros faces many challenges, but I hope that the government will draw encouragement from the example of other African countries that it is possible to tackle leprosy effectively. With political will from the top and greater involvement of the community as part of the solution, it can be done.

MOZAMBIQUE (July 24-28)

From the Union of Comoros I traveled to Mozambique. My last visit was in 2008, the year that this southern African nation achieved elimination of leprosy as a public health problem.

Unfortunately, Mozambique did not sustain its efforts against leprosy as its health priorities shifted elsewhere, and the number of cases began to increase. Compounding the situation, the previous national leprosy control manager was not immediately replaced after he retired.


Addressing a leprosy awareness rally in Nampula Province

However, under the current program manager, Dr. Francisco Guilengue (see sidebar), the government is recommitting itself to anti-leprosy activities, assisted by funding from the Bangkok Declaration Special Fund (BDSF).*

The good news is that Mozambique is still below the elimination threshold of 1 case per 10,000 population at the national level, although this is not the case in the north of the country, where three provinces—Nampula, Cabo Delgado and Zambezia—contribute 90% of new cases.

Before heading north to visit Nampula Province, I called on Health Minister Dr. Nazira Abdula in the capital, Maputo. I was pleased to receive from her a firm commitment to strengthen the program in light of the current situation—a situation made clear in a presentation by Dr. Guilengue.

In 2015, the year he was appointed national program manager, there were 1,335 new cases of leprosy; in 2016, new cases increased to 1,681; and in 2017, they rose to 1,926. Over the same period, the number of endemic districts in the country increased from 23 to 44. Furthermore, in the first six months of 2018, 951 new cases have been registered nationwide, compared to 684 in first six months of 2017.

As Dr. Guiengue explained, the increase in numbers is due to actions taken as a result of support from the BDSF to target highly endemic districts. These include mini campaigns, promoting village


With Mozambique Health Minister Dr. Nazira Abdula in Maputo

FOOTNOTE

* The Bangkok Declaration was issued in July 2013 following an international leprosy summit, with global experts and health ministers of endemic countries reaffirming their commitment to a leprosy-free world. The Nippon Foundation established a special fund following the summit to be used for early case finding and treatment in endemic countries.

(Right) Crowds welcome the Goodwill Ambassador to Namaita village; (far right) posing with health volunteers

leprosy days in remote areas, and involving self-care groups of persons affected by leprosy in active case finding. The program is also implementing a shift from paper to electronic record-keeping so that health workers have easy access to data via tablets and PCs.

But challenges remain: insufficient funding; the emergence of additional hotspots; poor knowledge of leprosy in many communities that results in delayed diagnosis and discrimination; medical personnel in endemic areas not adequately trained in leprosy; and lack of transport in endemic districts for active case finding and community visits.

Arriving in Nampula Province, I had a meeting with Governor Victor Borges, followed by a briefing at the provincial health department. There I learned that as a result of the increased activities of the program, there had been a 48% increase in cases in the province in the first six months of 2018 over the same period last year, up from 374 cases to 553. It now has the most cases of leprosy in the country.

Next I set out for Namaita, a village in the district of Rapale, to attend a rally promoting leprosy awareness. Around 800 people had gathered from Namaita and neighboring communities for an event that featured speeches, singing and dancing. Among those present were a group of persons affected by leprosy who told me they were grateful for the treatment they received but that more drugs were needed as there were still many cases of leprosy in the area.

When I spoke, I urged the crowd to check their families for any patches on the skin and go and have them examined by a health worker if they found anything suspicious. “Don’t hesitate to seek treatment. It’s free,” I told them. This was a theme I repeated later in the day during a live interview I gave to Radio Haq, an Islamic radio station, before leaving Nampula.

Back in Maputo, I continued my media work with another interview, this time for national television network TVM. The program was due to be dubbed into over a dozen local languages.

Resolving the issue of leprosy must involve the whole of society; it is not just an issue for doctors and patients. Politicians, school teachers, religious leaders and the media all need to be part of the solution. That said, it is important that the health ministry is firmly behind anti-leprosy efforts: therefore, I am grateful to Health Minister Dr. Abdula for the commitment she gave me during my visit and for the work now being undertaken by the program under Dr. Guilengue. ■

MAN ON A MISSION

When Francisco Guilengue was growing up, he did volunteer work for his church. A priest said he would make a good doctor and Francisco took his advice. Today Dr. Guilengue (photo) is in charge of Mozambique’s national leprosy program, a position he is happy to fill because of another childhood influence.

“My grandfather had leprosy. He developed deformity of the hands and feet. He lived with us, and my father and uncle did everything to support him, especially because my grandmother predeceased him,” he said.

“Having seen leprosy in my family, I’ve always had an interest in the disease. After I became a doctor, I encountered cases in the district where I was working, and wanted to know more about treatment and prevention.”

Dr. Guilengue thinks it was this interest that led him to be chosen as leprosy program manager in 2015—that and the fact that there were not many people lining up for the job. “Leprosy is a neglected disease; there are more resources in diseases such as malaria,” he says.

He is under no illusions as to the task he has taken on. “The biggest challenge we face is that the program went down after Mozambique eliminated leprosy as a public health problem and now we are having to put it back together. Among the public, not everyone knows about leprosy and what they need to do about it. And we need to explain to patients that they must complete their treatment.”

Finding new cases and treating them early to avoid disability is Dr. Guilengue’s priority. He is focusing on three endemic provinces in the north of Mozambique—Cabo Delgado, Nampula and Zambezia.

“Since our budget for case finding is limited, we are looking to involve self-care groups of persons affected by leprosy. I also want to involve religious leaders, school teachers and children,” he says, noting that some schools already provide pupils with body charts to take home to check the family for signs of leprosy.

The soft-spoken Dr. Guilengue is clearly keen to get his country’s leprosy program back on track and further equip himself for the challenge. “I want to improve my knowledge of public health and of leprosy,” he says. “I want to learn from those who have worked in leprosy a long time.”

NEWS

Reshaping the Law

Momentum building in India to end discriminatory statutes against persons with leprosy.

No country has more laws that discriminate against persons affected by leprosy than India, but recent developments give hope that change is on the way.

The Personal Laws (Amendments) Bill, 2018, which was submitted to the Indian Parliament on August 10 by Minister for Law and Justice Ravi Shankar Prasad, takes on one of the crueler penalties by looking to eliminate leprosy as grounds for the dissolution of marriage or divorce.

Five central laws currently contain such provisions: the Divorce Act (1869), the Dissolution of Muslim Marriages Act (1939), the Special Marriage Act (1954), the Hindu Marriage Act (1955), and the Hindu Adoptions and Maintenance Act (1956).

These are among 119 central and state laws that discriminate on the grounds of leprosy that have been identified by the Vidhi Centre for Legal Policy, an independent think tank based in Delhi. Since last year, India's Supreme Court has been considering a writ petition submitted by the Vidhi Centre to uphold the fundamental rights of persons affected by leprosy and repeal all discriminatory laws against them.

Many of these archaic laws are a legacy of colonial times and include provisions that disqualify persons affected by leprosy from election to municipal bodies, permit their removal from the governing board of universities and allow public authorities to prevent them from selling goods in a marketplace.

On August 20, the Supreme Court asked the central government if it would consider framing a comprehensive law to stop discrimination against persons affected by leprosy, with the government responding that legislation is in the process of being drawn up over the coming months.

As *The Hindu* newspaper cautioned in recent editorial on the subject, however: "It is possible to end discrimination by law, but stigma tends to survive reform and may require more than legal efforts to eliminate." ■

GLOBAL LEPROSY UPDATE

In 2017, 210,671 new cases of leprosy were reported, a 3.4% decrease from the previous year. India, Brazil and Indonesia accounted for 80.2% of new cases.

ONLINE READERSHIP SURVEY

We are carrying out a survey of our readers and would love to hear from you. The survey is available in English and Japanese. To access the questionnaire, simply place your smartphone camera over the QR code. If you don't use a smartphone, please email us at the address below using the header 'Readership Survey' and we'll send you the link. To those who select the English questionnaire, feel free to answer the questions in your own language if you prefer. Thank you for participating!

Email: smhf@tnfb.jp

FROM THE EDITOR

POLITICIANS TAKE NOTE

Dr. Alice Cruz, the UN Human Rights Council special rapporteur on leprosy, has been kept on her toes since her appointment last November. In addition to issuing her first report to the Council in June, she has found herself having to call out politicians for their use of leprosy as a metaphor.

First it was France's president, Emmanuel Macron, who said of nationalists that you could see them rise "a bit like leprosy all across Europe..." He was followed by Italy's deputy prime minister, Luigi Di Maio, who described what he called European "hypocrisy" over migrants as the "real leprosy." A few months later it was the turn of the Portuguese prime minister, Antonio Costa, and the Bangladeshi shipping minister, Shajahan Khan, who both used the term in reference to opposition political parties.

That politicians should reach for the word at all is testament to its staying power as a metaphor for all that is abhorrent, so deeply ingrained is its negative symbolism—and testament, therefore, to how hard it is to discourage its use. But as Dr. Cruz points out, politicians should choose their words carefully and avoid promoting misunderstanding of the disease, especially when their countries have approved the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members.

Let's hope the politicians—and everyone else—take note.

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