WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination
OF Leprosy

April 2019 • Number 94

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

Rafael Feitosa (right), director of former Brazilian hospital colony Tavares de Macedo, with long-time resident Dona Santinha in March (see page 6)

MESSAGE

Changing the Narrative

When I visited New Delhi in late January for the launch of the 14th Global Appeal, I was surprised by the number of times reporters asked whether leprosy is on the rise in India. The question seemed to have been triggered by leprosy case detection campaigns in the past two years that have identified many new cases of the disease. The perception among some members of the media is that leprosy is making a comeback in India.

But here is another explanation. The stepped-up activities of the National Leprosy Eradication Programme are producing results. Leprosy case detection campaigns, focused leprosy campaigns, and the Sparsh leprosy awareness campaign are detecting new cases earlier. It is not that leprosy has increased, but that surveillance has improved. The program is working.

What this means for the life of each person concerned cannot be overstated. With early detection, their chance of a complete recovery without residual disability goes up. For communities, the sooner persons are diagnosed and started on multidrug therapy, the sooner they stop being infectious.

With fewer cases of disability associated with leprosy, the disease becomes less frightening. This reinforces the message that leprosy is just another disease that can be treated and cured without residual consequences. This contributes to reducing stigma and discrimination.

"Leprosy on the increase" may be a headline that catches the eye of a newspaper reader. The real story, however, is that India is doing a better job of detecting cases today than in the 10 years since it was eliminated as a public health problem in 2005, when priorities shifted.

Yes, there is still a lot of hard work before we achieve a leprosy-free India, and yes, we need to be vigilant about leprosy reaction and other aspects of case management. But as I see the actions India is taking today, "leprosy making a comeback in India" is not what the media should be focusing on. Instead, we are seeing a temporary increase in case numbers because of the increased activities of the program, and that's a healthy sign.

— Yohei Sasakawa, WHO Goodwill Ambassador

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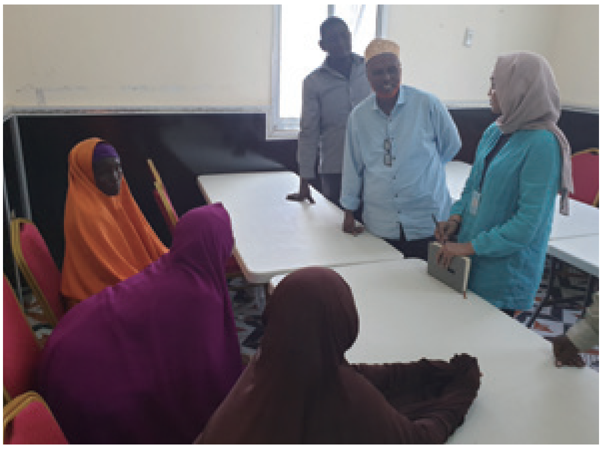
Somalia's Positive Steps

Case finding, treatment gather pace as government renews focus on leprosy.



WHO staff interact with female patients in Somalia, where there is a need to increase the number of female health professionals working in leprosy.

AUTHOR:
Dr Abdul Aziz Ahmed Aden
Dr. Aziz is the focal person for NTD control at the Ministry of Health, Federal Republic of Somalia

Sana (not her real name) was living in a camp for internally displaced persons (IDP) in Somalia's Banadir region when the patches that she had noticed all over her body since her late teens were diagnosed as leprosy.

Her diagnosis coincided with the revitalization of the country's health services after years of conflict, including reconstituting a national unit on neglected tropical diseases (NTD) with a special focus on eliminating leprosy.

Leprosy workers from the Ministry of Health's NTD unit made the diagnosis when they visited Sana's camp during a skin survey in May 2017. By then, however, her hands and feet were already severely deformed because the disease had progressed unchecked.

> Since the NTD unit was formed in 2015, around 5,000 new cases of leprosy have been discovered.

Before civil war forced Sana to move to the camp, she had sought treatment from local health practitioners for the patches. But the country's long-running conflict had led to a breakdown in general health services and many health practitioners were not familiar with the diagnosis of leprosy.

In the previous two centuries, the disease was limited to certain pockets of the country. However, new cases have emerged in different areas as a result of large-scale population movements caused by ongoing civil unrest and natural calamities such as drought, famine and flooding. Many of these cases are being found in camps such as Sana's, where an estimated 2.6 million people remain internally displaced.

Since the NTD unit was formed in 2015, around 5,000 new cases of leprosy have been discovered, rising from 107 in 2015 to 2,610 in 2018. This compares with just 14 cases found in 2014. The health ministry expects case numbers to increase over the coming four to five years as coverage improves before new-case detection plateaus.

IDP camps in Mogadishu, the capital, and seven other regions—Banadir, Middle and Lower Shabelle, Middle and Lower Juba, Bay and Hiran—have been covered since these are areas known to be endemic for leprosy. In the coming months, the ministry is confident of being able to cover all the camps in the country and extend activities nationwide.

Challenges remain, however: sufficient funds are needed to mobilize staff in different parts of the country where they are needed; ongoing conflict in some areas makes the safety of staff a concern; leprosy is just one of a number of competing health issues that need to be addressed; deep-seated stigma compounds the problems the program faces; there is a need to increase the number of female health professionals to be able to reach out to women and children affected by leprosy; and many of those working in leprosy are volunteers who may move on because they need to find work to support themselves.

The WHO works in tandem with the Ministry of Health in implementing health services. Under country representative Dr. Mamunur Rahman Malik, it emphasizes providing leprosy services—diagnosis, treatment, prevention of disability and rehabilitation—to all in need through primary health care, in line with the goal of universal health coverage.

Meanwhile, all efforts are being made to access support from bilateral aid agencies and institutional donors to strengthen infrastructure and the national program. Currently, there are no partners working on leprosy in Somalia since World Concern left in 2013.

"We welcome partner agencies to join the Ministry of Health in combating leprosy in the country," says Health Minister Dr. Fawziya Abikar Nur, who stresses that the ministry is willing to support any such organization to work in Somalia by expediting the granting of the necessary permissions.

She also has a message for the Somali public: "The government is determined to provide multidrug therapy treatment to all patients suffering from leprosy; likewise, we are committed to provide disability care for those in need and eliminate all forms of discrimination against persons affected by leprosy in the community."

While Sana's diagnosis came too late for her to avoid life-long disability, Somalia's renewed efforts against leprosy offer hope that new patients will be detected and treated in timely fashion so as not to share the same fate. ■

The Personal Touch

Involving persons affected by leprosy in case finding has many benefits.

AUTHOR:
Ben Kritz
Ben Kritz covered the recent Regional Assembly of Organizations of People Affected by Leprosy in Asia for Inter Press Service (IPS) News Agency, which published the original version of this story.

Jennifer Quimno could put anyone at ease. So when she travels across the Philippines as part of a peer-to-peer program that helps identify new leprosy cases, people generally allow her to examine them.

"We met a young boy, about 16 years of age, who had symptoms of leprosy, and we needed to examine and send pictures of his skin rashes to the doctors for diagnosis," Quimno said. Having once had leprosy herself, Quimno was able to put the teenager at ease. "One of his rashes was on his buttocks. He was a little embarrassed to show it at first, but when I asked him nicely, he let us take a look."

We can tell them exactly what the consequences of not seeking timely treatment will be.

That unique sensitivity toward persons affected by leprosy is a valuable resource in identifying new cases and encouraging patients to seek treatment, Frank Onde, the president of the Coalition of Leprosy Advocates of the Philippines (CLAP), explained.

"Strengthening the participation of persons affected by leprosy is the most effective way to reduce the burden on government health departments," explained Onde, one of the keynote speakers at the Regional Assembly of Organizations of People Affected by Leprosy in Asia that was held in Manila, the Philippines, from March 3 to 5.

Under the program organized by CLAP, former patients are trained in community outreach and help to identify potential cases for diagnosis and treatment. Using people who have personal experience with leprosy helps to reduce the reluctance of those with the disease to seek treatment, Onde said. Not only can the outreach workers relate on a personal level with others affected by leprosy, their own experience also helps healthcare personnel make accurate diagnoses, he added.

Launched in the cities of Manila and Cebu in November 2018, the program, 'Strengthening Participation of People Affected by Leprosy in Leprosy Services', known as SPP, is currently working among known affected communities. It pursues the twin objectives of gathering demographic information to update the Philippine Department of Health database and identifying relapsed or new leprosy cases.

CLAP President Frank Onde (left), and CLAP volunteers Mark Anthony Esparas (center) and Ariel Lazarte (right). Credit: Ben Kritz/IPS

CLAP community outreach organizers Jennifer Quimno (left) and Michelle Ann Oreo (right). Credit: Ben Kritz/IPS

Quimno, who is a field health officer with the Department of Health's regional office in Cebu, said that personal experience helps to build trust. "We know what they are experiencing," she explained. "We can also tell them exactly what the consequences of not seeking timely treatment will be."

GRASSROOTS CONNECTIONS

While CLAP's activities are officially supported at the national government level—the coalition is represented on the Department of Health's National Leprosy Advisory Board—it is at the smallest level of government where the initiatives of the coalition's individual organizations are substantially embraced.

"We coordinate with local government units at the municipal and *barangay* [village] level, including the mayor's office and the city or municipal health official's office," Quimno explained. "Since our individual member groups are the ones doing most of the work right in their own communities, they are really embraced by their local officials."

Mark Anthony "Macoy" Esparas, a CLAP outreach volunteer in Manila, agreed. "We do receive a lot of help from the local governments," he told IPS. "What we do is helping them as well."

CLAP advisor Joseph "Boyet" Ongkiko highlighted the success of one CLAP member group in Cotabato, Mindanao, southern Philippines, which formed a cooperative of motorcycle taxi drivers to provide livelihoods for people affected by leprosy. "At first, the community was reluctant to patronize the drivers," Ongkiko told the conference attendees. "Now, they have been accepted so well, that the cooperative even has non-Hansenite members."

Other livelihood activities pursued by the member groups of CLAP—the coalition represents a total of >>

Help for the Vulnerable

A new committee seeks to help Brazilian immigrants affected by leprosy.

Last year I was put in touch with Cátia, a 32-year-old Brazilian immigrant living in Paris. In the past, she had been treated for leprosy in Brazil. But for more than a year she had been experiencing a loss of tactile sensitivity and muscle strength in her hands and feet.

As soon as she got her French residency papers, she sought medical care. Cátia, who took the anti-inflammatory drug prednisone for many years and had undergone surgery on the nerves in her legs, saw several doctors in Paris and told them she believed her condition was related to Hansen's disease. According to her, some doctors did not know what Hansen's disease was; others doubted that she had the disease because she had no skin lesions.

After a week of searching, I was able to have Cátia seen by the doctor responsible for leprosy services in Paris at the dermatology outpatient clinic at the Hôpital Saint Louis. She was asked for her medical records from Brazil, which she did not have.

At time of writing, Cátia awaits a medical decision on her case, and she has already received a bill for 650 euros from the French public healthcare system. She has many concerns and we talked several times. Recently, she called me because she feared that her past use of clofazimine (one of the drugs used in multidrug therapy to treat leprosy) had caused color blindness in her son.

I received other phone calls and heard similar stories. In all cases, the challenge was how to put Brazilian immigrants affected by leprosy, or who suspected they might have the disease, in touch with the appropriate doctors.

But as Cátia's case shows, the challenges don't stop there: they also include the cost involved, the documentation required, and the fact that doctors in Europe don't encounter many cases of the disease.

On top of that, there is the question of terminology: Brazilians refer to the disease as hanseníase (Hansen's disease) and consider it different from leprosy with its biblical associations that may color the way even health professionals look at the disease and those who contract it.

MORE HUMANIZED APPROACH

I discussed the situation with the Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN) in Brazil and together with Evelyne Leandro (*see sidebar*) we created CAIBAH—the Committee to Assist Brazilian Immigrants Affected by Hansen's Disease. Formed at the end of last year, this committee has the potential to promote a more humanized and less bureaucratic approach to assisting Brazilian immigrants affected by leprosy and their families in France and other European countries.

Immigrants affected by leprosy, whether they have been diagnosed or not, are in a situation of extreme vulnerability, not only because they are ill, but also because they are immigrants. This is especially true of involuntary immigrants who were forced to leave their home countries. This category of immigrant often suffers from a slow, painful and poverty-stricken adjustment process. They are without documents, relatives, or friends; they have communication difficulties; they lack money, legal domicile and opportunities; and the local population sometimes likens them to criminals.

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19 local organizations across the Philippines—include production and marketing of various household products, clothing, and small-scale farming.

FINANCIAL SUSTAINABILITY CHALLENGE

While CLAP's initiatives are steadily gaining traction among people affected by leprosy and local communities alike, the organization is concerned about its prospects for sustainability.

"That is our biggest challenge right now," Onde said. "At the moment, our financial support is really only coming from the Sasakawa Health Foundation (SHF) and we would like to better secure our future." SHF, along with its parent body The Nippon Foundation, co-sponsored the assembly along with the Philippine government-run Culion Sanitarium and General Hospital (CSGH) and CLAP.

Financial sustainability is a common worry for leprosy advocacy groups throughout the region, but in the Philippines, Onde explained, CLAP and other organizations face a unique challenge. In 2013, a large-scale conspiracy dubbed the "Pork Barrel" scam and involving the misappropriation of billions in legislators' development funds was exposed. Funds intended for local projects were diverted to fabricated non-government organizations and then pocketed by the scam perpetrators, including a number of lawmakers.

"Since the Pork Barrel scam, it has become difficult for a lot of civil society groups, not only us, to attract donors," Onde said. "So one of our important tasks is to try to share information about what we're doing to convince potential financial supporters that we are a legitimate, sustainable organization."

One advantage for CLAP is its close connection to the government's own leprosy control efforts. "We have a consultative role in the government's National Leprosy Control Program and the Leprosy Roadmap 2016-2022," Onde said. "That does help give us some credibility, and of course, we strive to do good work to match that." (Inter Press Service) ■

To spread the word about CAIBAH, and find out how it could operate effectively, I contacted doctors and hospitals, as well as Brazilian diplomats, priests and associations in France. I also spoke with Brazilians from different socioeconomic and educational backgrounds, and distributed basic information about signs and symptoms of the disease.

> I contacted doctors and hospitals, and Brazilian diplomats, priests and associations in France.

CAIBAH is in its early stages and still finding its way forward. We currently have 12 members who bring different skills to bear. I am a Brazilian leprologist currently undertaking research in Paris; Evelyne has experience of being an immigrant with leprosy; Alice Cruz, the UN Special Rapporteur on elimination of discrimination against persons affected by leprosy, is also on the committee.

We can take simple, low-cost actions initially, but they depend on the goodwill of those involved. CAIBAH needs to become a multilateral committee that can integrate health professionals and patients in a harmonious way, reducing the distance between them. Ideally, in addition to being able to refer patients to doctors, we would like doctors to let their patients know about CAIBAH.

While this initiative was started with Brazilian immigrants in Europe in mind, in the future I would like to see CAIBAH superseded by a committee for all immigrants affected by leprosy, so that these issues can be resolved effectively for everyone. Hence I welcome the recent developments in Rio de Janeiro that Evelyne describes below.

For more information, contact: imigrantes.hanseniase@gmail.com ■

A SHOULDER TO LEAN ON

In 2012, two years after moving to Germany from my native Brazil, I was diagnosed with leprosy, *writes Evelyn Leandro*. I was beginning to find my feet in my new home and the diagnosis came as a shock.

I went through a lot and wrote a book about my experiences. That's why, a few years later, when Artur Custódio, national coordinator of MORHAN, invited me and Dr. Patricia Deps to start the Committee to Assist Brazilian Immigrants Affected by Hansen's Disease (CAIBAH), I accepted immediately.

As an immigrant myself, I would very much have liked CAIBAH to have existed in 2012. It acts as a support network, serving as a platform for exchanging experiences, information and contacts, thus shortening the path between diagnosis and cure. It also offers a friendly hug or a shoulder to lean on—even if only virtually—at the most difficult times.

Being away from home is not easy. The challenges associated with learning a new language and acclimatizing to a new culture can be great. A problem takes on another dimension—especially when it turns out to be leprosy.

In the year I was diagnosed, four other people in Germany were also diagnosed with the disease, among them a 13-year-old boy from Brazil. In Portugal, there is an average of 10 new cases per year. In Spain, six new cases were reported in 2018, among them three Brazilians and one Paraguayan.

The actual number of cases may well be higher, given that not many doctors are trained in leprosy. In my own case, I had been examined several times and the doctors still did not know what I had, when I emailed my mother 8,000 kilometers away with my symptoms. Having seen ads for World Leprosy Day on Brazilian TV, she suggested I might have leprosy. If it wasn't for her, perhaps my diagnosis would have taken much longer and I would now be living with more serious consequences.

Dr. Deps encountered a similar situation in Paris recently in the case of Cátia, the Brazilian woman who suspected she had fallen ill with leprosy again. Had it not been for Dr. Deps' intervention, Cátia may well have had to wait months for an appointment—and time is something we cannot afford to lose in such cases.

GLOBAL ISSUE

Migration is a topic discussed every day in Europe. A German minister months ago described it as the mother of all problems. Naturally, he had to explain himself afterward, but the bitter taste remains.

This is not just an issue for Europe. Given the current situation in Venezuela, for example, migration and access to health services by immigrants is also a current issue for the Americas. We need to broaden the scope of our activities.

That's why I am very pleased that at the recent Regional Assembly of Latin America/Caribbean Organizations of People Affected by Leprosy, where I made a presentation on CAIBAH, the following proposals were approved: to expand the work of the committee by founding a Latin American and Caribbean Network for the Protection of Immigrants Affected by Leprosy, and to encourage the creation of committees to assist immigrants affected by leprosy in all regions, regardless of the immigrant's origin.

I was lucky. I had access to good doctors and hospitals in Germany. But even so, I felt very alone throughout my treatment. Seven years later, I still get emotional thinking about it. But we can't count on luck all the time. That's why we need CAIBAH.

Evelyne Leandro is a project officer at Bread for the World (Brot für die Welt) in Berlin.

Leave It to Rafael

A Brazilian hospital director shows that where there's a will, there's a way.

In 2017, prospects looked bleak for Hospital Tavares de Macedo in Rio de Janeiro's Itaborai municipality. The former hospital colony, one of 33 where Brazil used to send Hansen's disease patients into compulsory isolation, faced closure.

There were less than two dozen elderly residents staying in the wards and another 200 housed on the sprawling grounds. The outside community had "invaded", taking over vacant buildings and bringing criminal activity with them. The health secretary of the local municipality had never visited, and it was costing money that Rio de Janeiro didn't want to spend.

Enter Rafael Feitosa, a practicing lawyer and a volunteer with MORHAN, the Movement for the Reintegration of Persons Affected by Hansen's Disease. MORHAN's national coordinator, Artur Custodio, persuaded Rio's state health secretary to give the hospital one more chance and proposed appointing Feitosa as director. "He's not a doctor. He knows the people living there. He talks a lot," Custodio told him.

The secretary expedited the paperwork and two days later Feitosa was on his way. Run down, unsafe, short of supplies and lacking basic amenities, Tavares de Macedo was about to get a makeover.

Hospital director Rafael Feitosa. "He's not a doctor. He knows the people living there. He talks a lot."

SITTING DOWN WITH STAFF

Feitosa began by talking to each member of staff in turn—some 200 public servants directly employed by the state and around 140 employees of private contractors carrying out various jobs at the hospital. He asked them if they knew about Hansen's disease, about the history of hospital colonies and the lives of those affected by the disease. If they knew nothing and expressed no interest in learning, he made it clear they should think about working elsewhere.

He was already on friendly terms with the residents. Having answered calls on the Telehansen helpline run by MORHAN for seven years, he had talked with them often. Now, as director, he was in a position to do something for them, beginning with sprucing up the wards.

"Paint was peeling off the walls and there was no air conditioning," he recalls. So he had the wards redecorated and persuaded a company to donate 12 air conditioners—and the company even agreed to cover the cost of installing them.

Another change was to have a new refectory built, since the old one had been condemned as no longer fit for purpose and Feitosa thought it would be good for residents to socialize. "We still need additional tables and chairs, though, so that more people can eat together at the same time," he says.

Feitosa's efforts have not just benefited the hospital's long-term residents but also the surrounding community, for whom it functions as a general hospital. There are now adequate supplies of medicine and bandages; a histology lab has opened; and there is a vaccination clinic among other services.

Locals have noted the improvements and become aware that this is not just a hospital for Hansen's disease. When Feitosa took over as director, it was seeing around 1,000 outpatients a month. Less than two years later, the figure is up to 5,000 and now he is targeting 7,000.

On a whiteboard in the outpatient clinic is a handwritten mantra about "humanized care." Its message is simple: people who come here are not just patients but have a life outside the hospital. They are a mother, a father, a grandmother, a grandfather, the love of someone's life. When they come through the door, they are the most important people in the hospital and need to be respected.

"I've assigned more staff to talk to the outpatients, get to know their lives and find out how they and their families are doing," Feitosa says. Given the dangers that lurk nearby in the form of drug dealers and gang activity, there is self-interest involved too, as knowledge of who's who helps protect staff.

As he tours the hospital Feitosa has a nod and a friendly word for patients and staff alike. "I talk to staff here all the time, emphasizing the importance of how they treat the patients." Once a month, he gathers them together to discuss what they could be doing better. "My door is always open."

A BEAUTIFUL CAUSE

Feitosa, who studied law while driving a cab in Rio and continues to practice while running the hospital, became involved with MORHAN through his wife. "It's a beautiful cause. I have come to love the people I have met who have had Hansen's disease. I'm here to do my best for them."

For those elderly residents such as Dona Santinha (see cover photo) living out their days at Hospital Tavares de Macedo, that includes Feitosa picking up the phone from time to time and reminding a family member of their filial obligations. "I am the hospital director," he tells them. "Hey, you need to come visit your mother sometimes." ■

AMBASSADOR'S JOURNAL

A Visit to Bangladesh

The Goodwill Ambassador flies to Dhaka to propose a national conference on leprosy to redouble efforts against the disease.

BANGLADESH (February 9-13)

In February I traveled to Bangladesh. One of the reasons for my trip was to lay the groundwork for a national conference on leprosy later this year, similar to the conference held in Myanmar last December (see below).

During my stay in the capital, Dhaka, I called on Prime Minister Sheik Hasina Wazed, Speaker of Parliament Dr. Shrin Sharmin Chaudhury and Health & Family Welfare Minister Zahid Maleque to discuss my suggestion for a conference and give encouragement to the government to further strengthen medical and social initiatives against the disease.

> Finding hidden cases is now a priority. A national conference will help to raise awareness.

Bangladesh achieved the elimination of leprosy as a public health problem in 1998, but annual new case numbers have leveled off in recent years, in line with the global trend. Specifically, it sees around 3,000 to 4,000 new cases a year, with many found in the northwest and the southeast of the country.

Finding hidden cases is now a priority for Bangladesh. This is why I believe a national conference will be important in helping to raise awareness of leprosy, refocus efforts against the disease and increase momentum toward the goal of a leprosy-free Bangladesh. I very much hope the prime minister will lend her support by attending.

With Prime Minister Sheik Hasina Wazed in Dhaka

While in Dhaka, I also met with the executive director of the influential developmental organization BRAC (Bangladesh Rural Advancement Committee), which is dedicated to alleviating poverty by empowering the poor to bring about change in their own lives. BRAC has an impressive network of 45,000 field workers and we discussed the possibility of it becoming involved in efforts against leprosy and also in the social rehabilitation of persons affected by the disease. Happy to report, these talks were very constructive. ■

TARGETING DISCRIMINATION IN MYANMAR

At the end of last year I took part in a National Leprosy Conference held in Myanmar's capital Nay Pyi Taw. Organized by the Ministry of Health & Sports with support from The Nippon Foundation, the December 12-13 gathering brought together top government officials, leprosy experts from inside and outside the country, and persons affected by leprosy with the aim of reinforcing commitment to fighting the disease and the deep-rooted stigma it attracts.

State Counsellor Aung San Suu Kyi gave the opening address in which she said that efforts to stop discrimination against persons affected by leprosy and their families should be a top priority. She also called for the public to become better informed about the disease.

Myanmar currently detects around 2,000 to 3,000 new cases annually. I understand that around 90% of these are found in high disease-burden areas: Ayeyarwaddy, Bago, Sagaing, Mandalay, Magway, Yangon Region and Shan State.

At the end of 2017, there were 2,216 registered cases and the prevalence rate per 10,000 population stood at 0.42. Of new cases, the proportion of child cases stood at 3.5%, cases with Grade 2 disability at 12.4% and females at 30%.

Stigma and discrimination continue to be a barrier to early detection and successful completion of treatment, with many persons affected by leprosy experiencing social exclusion, depression and loss of income.

State Counsellor Aung San Suu Kyi greets U Soe Win, who heads an organization for disabled persons in his village in Myanmar.

"Join hands to stop discrimination" was the motto of the conference. Thus I was delighted to see the state counsellor stay on after her address to speak with persons affected by leprosy, hear their stories and shake their hands.

NEWS

Power to the People

Three regional assemblies seek out what matters to persons affected by leprosy.

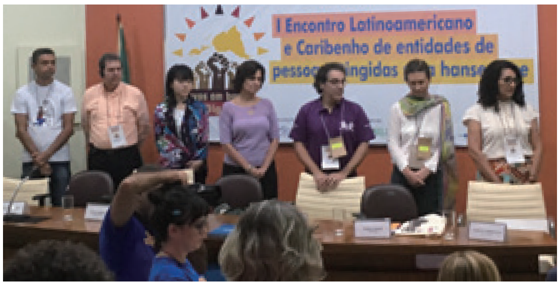
What are the challenges facing organizations of persons affected by leprosy in different parts of the world, what are their aspirations and how can they go about achieving them?

Between January and March this year, Sasakawa Memorial Health Foundation (known as Sasakawa Health Foundation, or SHF, since April 1, 2019), organized three regional assemblies of people's organizations in Africa, Asia and Latin America/Caribbean to find out what issues they prioritize.

The goal is to identify and formulate proposals for discussion at a world assembly of people's organizations sponsored by SHF ahead of the 20th International Leprosy Congress in Manila this September.

Doing so, SHF hopes, will provide national governments, international organizations and NGOs with a clearer picture of the current role and standing of people's organizations going into the triennial gathering of the world's leprologists, as well as lead to the creation of regional and international networks of people's organizations that will strengthen efforts against the disease, advance social inclusion and combat discrimination.

Meeting in Addis Ababa, Manila and Rio de Janeiro, respectively, people's organizations from some 15 countries took part in the assemblies, during which a wide range of issues were raised.



These included questions involving terminology—ranging from concerns about the expression "person affected by leprosy" to a debate over whether "leprosy" should be replaced by "Hansen's disease" because of the former's stigmatizing associations; the issue of whether and how people's organizations can sustain themselves; and a proposal to assess mental health status when grading disability in relation to leprosy.

For some of these organizations, it was the first time they had come together to discuss issues they share in common. As a result, all three assemblies ended in agreement to pursue the formation of regional networks to build on the links that had been created.

It remains to be seen what proposals emerge from the world assembly planned for September, but SHF hopes that this initiative will give people's organizations a platform on which to set out their collective agenda and help shape policy toward leprosy and those affected by the disease in the years to come. ■

FROM THE EDITOR

CHANGING LIVES, CHANGING THE WORLD

When Lucrecia Vasquez took the floor on the final day of the recent Regional Assembly of Latin American/Caribbean Organizations of People Affected by Leprosy held in Rio de Janeiro, she spoke from the heart.

Representing Felehansen, an organization from Colombia, she told delegates: "I never imagined I would be in Brazil, because when I was diagnosed with leprosy, I thought my life had ended. But look at me now. My life has changed. And that is what we want: to change lives."

With that comment, Lucrecia got to the core of what motivates organizations of persons affected by leprosy such as hers and why they understand the part they can play in combating leprosy and the stigma that accompanies it. Based on their own experiences, they are well placed to help others, who like Lucrecia once did, may feel that their life has ended because of a diagnosis of leprosy.

"Organizations such as ours have such an important role. We need to be strong and offer support to the people," she said. "I am sure that health organizations will appreciate that we are part of the fight against the disease."

It is particularly hard when persons affected by leprosy are not part of the decision-making process, she said, and there need to be more opportunities for participation. That's why Felehansen reaches out to all sectors—from health to education to the church—to involve persons affected by leprosy in activities where they can make a difference. Where leprosy is concerned, "we should be the main protagonists."

Beyond changing lives, Lucrecia challenged delegates to be more ambitious still. "If, every day, we contribute love and happiness, think how much we could change the world."

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