

FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador receives a gift from Sorofo Self-Care Group of people affected by leprosy in North Maluku Province, Indonesia, in July 2017.

MESSAGE

CONTENTS

My Hopes for the Special Rapporteur

In September, the UN Human Rights Council appointed a new Special Rapporteur on elimination of discrimination against persons affected by leprosy and their family members. Out of 11 excellent applicants, the council chose Dr. Alice Cruz of Portugal.

Since Old Testament times, leprosy has been a highly stigmatizing disease. While case numbers have come down dramatically in recent decades through efforts led by the WHO and the effectiveness of multidrug therapy, it is no exaggeration to say that the discrimination persons affected by leprosy face has been overlooked until now.

In 2003, I approached the then UN Commission on Human Rights to seek its support in tackling this issue. Transcending politics, religion, ethnicity and national boundaries, leprosy-related discrimination was a huge problem and unknown to people the world over. Thanks to the cooperation of the Japanese government, a resolution on elimination of discrimination against persons affected by leprosy and their family members was adopted by the UN General Assembly in 2010 with the unanimous support of 194 countries.

Subsequently, Mr. Imeru Yigezu of Ethiopia,

a member of the UNHRC Advisory Committee, spent two years compiling a report on the extent to which countries were implementing the Principles and Guidelines that accompanied the 2010 UN resolution. In his report, he strongly recommended the appointment of a Special Rapporteur.

As the UN faces financial constraints, there was a negative attitude toward establishing a new, additional mandate. However, the resolute efforts of Japan's foreign ministry and Ambassador Mitsuko Shino in Geneva won the understanding of member countries, resulting in Dr. Cruz's appointment. I very much appreciate this decision and the cooperation of all who were involved in this process.

I look to Dr. Cruz in expectation that she will grasp the realities of the situation in each country as best she is able—in particular, investigating any discriminatory laws, institutions and practices that remain—and help pave the way for persons affected by leprosy to live in a truly inclusive society without discrimination. Let all of us support her in this work.

— Yohei Sasakawa, WHO Goodwill Ambassador

Message	1
Interview Dr. Alice Cruz UN Human Rights Council Special Rapporteur on leprosy	2
Ambassador's Journal Return to Indonesia	6
News Global leprosy update 2016; India national leprosy conference announcement	8
From the Editor	8

'You Need to Reach Deep Waters'

The new Special Rapporteur on leprosy discrimination prepares to take the plunge.

Why did you apply for the position?

It was something I felt I had to do, following years of personal, academic and activist engagement with persons affected by leprosy. Over that time, I have come to know the structural barriers they still face to a full life, and the way these disrupt their individual lives, bodies and identities. I have also come to know how difficult it is to remove these barriers.

However, for vulnerable persons who face multiple discrimination in their daily lives, there is no time to lose. This newly created mandate for a Special Rapporteur represents an opportunity to act quickly under the United Nations system. It also represents an exceptional opportunity to promote the role of states in changing the structures that frame the way society looks at, and relates with, persons affected by leprosy.

What qualities do you bring to the post?

In order to tackle leprosy-related discrimination, you need to reach the deep waters where leprosy's experience interacts with structural conditions. You just can't stay at the surface of things, because you're looking for more than mere conjunctural adjustments, although they are also necessary. You're looking for a structural change in the minds of people that might ensure the sustainability of social inclusion. Moreover, not only is leprosy-related discrimination multilayered and made manifest in different spheres of society, its experience is also composed of several layers of bodily experiences, emotions, relational dynamics, challenges, human rights violations, and struggles for dignity that are frequently silenced in the public sphere.

I consider the main quality that I bring to the post is my experience at the grassroots.

The practices and strategies required of a UN Special Rapporteur don't afford the time for such in-depth comprehension. Therefore, I believe my previous academic and activist experience has prepared me to grasp rapidly the framing of leprosy's experience on different scales—individual, social, medical, state—and in different historical, regional and cultural settings.

But what I consider the main quality that I bring to the post is my experience at the grassroots. Working in Brazil with one of the most effective social movements of persons affected by leprosy, MORHAN (Movement for the Reintegration of Persons Affected by Hansen Disease), enabled me to understand leprosy, its experience and its governmentality in ways beyond the reach of a

strictly academic view. I also learned to take action toward eliminating discrimination and its exclusionary factors. Finally, I believe that having a UN Special Rapporteur who comes from the grassroots will be in itself empowering for persons affected by leprosy.

Tell us more about your background in leprosy and human rights.

I've devoted almost all of my academic and professional life to leprosy. My Master's thesis is on the prophylactic model that imposed the compulsory segregation of persons affected by leprosy throughout the twentieth-century. It analyzes the biopolitical project behind it and reveals the life stories of people who still inhabit former leprosy colonies.

My PhD thesis identifies, in countries where leprosy is an endemic neglected disease and in countries where it is an imported and rare disease, the different barriers preventing persons affected by leprosy from accessing early diagnosis and high-quality care, as well as their social, economic, family and personal circumstances.

I have been engaged also with the rights of other vulnerable groups, such as indigenous women and children, researching interculturality as key to the promotion of maternal and child health. That helped to deepen my understanding of gender, age and cultural issues in leprosy.

Working as a volunteer with MORHAN, I have studied good practices, such as the indemnification granted by Japan's government to persons affected by leprosy who were segregated in the past, and its influence on Brazilian Federal Law 11.520.* I also worked on the development, monitoring and evaluation of projects aimed at eliminating leprosy and the stigma attached to it, and participated in the development of WHO guidelines for strengthening participation of persons affected by leprosy in leprosy services.

In addition, I translated into Portuguese UN Resolution 65/215 on elimination of discrimination against persons affected by leprosy and their family members, as well as the accompanying Principles and Guidelines, and worked for their dissemination in Brazil. I also helped to organize the first in a series of regional symposia on leprosy and human rights, held in Rio de Janeiro in 2012. Plus, between 2014 and 2016, I served as a member of the International Leprosy Association's Council, where I always advocated for the participation of persons affected by leprosy in scientific meetings and health services.

What do you see as the key steps to ending discrimination against persons affected by leprosy?

First, I believe it is necessary to overcome the idea that leprosy-related discrimination is a consequence



PROFILE

Dr. Alice Cruz was recently appointed by the UN Human Rights Council as Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. A medical anthropologist and researcher, she has done extensive work on the biopolitical and biosocial aspects of leprosy. A Portuguese citizen, she currently teaches at the Law School of University Andina Simon Bolivar in Ecuador.

FOOTNOTE

* This September 2007 law granted a pension to persons who had been compulsorily isolated in hospital-colonies prior to 1987.

of the disease and/or of the fear it might generate. Stigma and discrimination are socially constructed. They are a product of history. As such, they are contextualized on the one hand and inseparable from social hierarchy and inequities on the other; that is why Paul Farmer speaks of health-related stigma as the tip of the iceberg. The question is: how to access, and change, what lies beneath the surface.

Stigma and discrimination are socially constructed. They are a product of history.

I would say we could set short-, medium- and long-term goals. Regarding the short- and medium-term goals, it is important to identify in which social sphere discrimination occurs. Is it on the macro level of the state, whether in the form of discriminatory laws and jurisprudence, ineffectiveness of already recognized rights, and/or mistaken public policies? Is it on the intermediary level of state goods and services, such as health services, education, work opportunities and regulation? Is it on the micro level of community life and/or the family? And are persons affected by leprosy struggling with institutional discrimination, public discrimination, iatrogenic discrimination, affiliated discrimination, or with a more widespread structural violence manifested in multilayered discrimination?

In order to know the answers to these questions, it is mandatory to listen to what persons affected by leprosy have to say. They are better positioned to identify the features of discrimination in concrete social spaces.

We also have an important instrument that allows us not only to assess discrimination on different levels of social organization, but also to take immediate action, when needed, as well as to design intervention plans. This is the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy

and their family members. This instrument should be accessible in terms of language to persons affected by leprosy, in order for them to include it in their daily struggle to claim their rights. But it must be used in accordance with context, which means that its implementation is not independent of the heterogeneity of the modern state in different historical and cultural contexts.

Another important issue concerns the vulnerability of persons affected by leprosy, which relates to what I mentioned before as structural violence. Persons affected by leprosy tend to be the most vulnerable members of society. I won't go deeper into this point here, other than to say we also have an important instrument to address, in the medium and long term, the issue of vulnerability, which is the UN Sustainable Development Goals.

Having said all this, I would still like to mention the bottom of the iceberg. At the base of the discrimination against persons affected by leprosy seems to be the feeling that they are persons apart. For centuries, the frontier that symbolically separates those who have leprosy from those who don't was set in stone, homogenizing them, silencing them, and rendering the idea of exclusion as something natural. This goes back to what I said earlier, which is that discrimination is a product of history.

So what can be done?

It has been demonstrated that interaction at the micro level is one of the most effective strategies in overcoming the automatic response of rejection, by showing that what we considered apart is, in reality, similar to us. This can be scaled to awareness programs that tear down those stone barriers.

That is why participation of persons affected by leprosy is critical in educational and awareness programs, as is their right to memory as an educational strategy. That is why we need to be careful about language. That is why empowerment of persons affected by leprosy is key to eliminating discrimination.

This means ensuring the right to education and employment, the right to safe housing, the right to land in former leprosy colonies, the right to high-quality care that encompasses access to early diagnosis and care after release from treatment, the right to welfare benefits during treatment and after, as needed—in other words, equal opportunities to participate in society.

Finally, the right to participate in decision-making that concerns persons affected by leprosy is crucial for achieving sustainable inclusion. Only with persons affected by leprosy as the main protagonists of historical change will we hopefully eliminate leprosy-related discrimination. >>



Portugal's former hospital-colony Rovisco Pais as it looked in 1947: Cruz carried out ethnographical and documentary research here between 2006 and 2008.

Do you think leprosy-related discrimination can or should be seen in isolation from discrimination caused by other diseases and conditions?

No. I believe that is why the medicalization of stigma attached to leprosy—that is, the idea that availability of treatment and dissemination of medical knowledge about the disease would be enough to eliminate discrimination, wasn't sufficient. While we can't dismiss the groundbreaking role of multidrug therapy (MDT) in the lives of persons affected by leprosy, as well as its impact on the public's image of the disease, discrimination persists. In order to understand that, we need to look at the ways through which stigma and discrimination are socially constructed, and we also need to look at how leprosy intersects with other vulnerabilities.

Since there aren't very relevant syndemics between leprosy and other diseases—as there are in the case of TB and HIV, for instance—it is more important to look at the intersection of leprosy with gender, age, disability, racial and ethnic belonging, and class. The idea of intersectionality is intended to show how when a person affected by leprosy is a woman, or a woman with a low level of education, this makes her more vulnerable to discrimination than if she were, for example, a white, highly educated man.

We need to look at how leprosy intersects with other vulnerabilities.

From the point of view of advocacy directed at transnational agencies or at state health programs, it is important to point out that leprosy is a neglected disease suffering from underfunding in research, and also to promote public awareness by linking leprosy to more socially visible diseases in public health campaigns. But in the case of leprosy-related discrimination, it would be more effective to direct action toward the intersection of leprosy with other subaltern social conditions. That is also one of the reasons why this newly created mandate at the UN is a remarkable opportunity: it allows working the intersectionality of leprosy with other social experiences that are structurally exposed to violations and/or denial of rights, through internal and external cooperation.

Are there any individuals, stories or experiences that have had a particular impact on you in shaping your views on leprosy, and on human rights?

The difficulty is to choose. I was a young researcher when I arrived at the former hospital-colony Rovisco Pais, the last Portuguese leprosy colony. There, I found one mentor, Mr. Abel Almeida. Mr. Abel was taken away from his family at a very early age and spent almost all his life in medical institutions, under compulsory internment. As he used to say, he was treated by the Portuguese state as a criminal; his “crime” was having leprosy.

Inside the former hospital-colony, Mr. Abel became a leader for the women and men who lived there, and achieved significant changes in the strict organizational model of the hospital-colony that allowed residents to access improved quality of health and life. He wrote a personal letter to Pope Pius XII, asking the Catholic Church to stop using the word “leper.”

Another great man who transformed my worldview was Mr. Cristiano Torres, one of the founders of MORHAN. Despite also having been separated from his family at an early age and having suffered from forced segregation, Mr. Cristiano had a fighting and joyful spirit that wasn't weakened by hardship. With Mr. Cristiano, I discovered the political maturity of the founders of MORHAN who, with unusual clarity of thought, undertook remarkable steps toward social recognition. They made it possible for persons affected by leprosy in Brazil to have the right to claim rights. Mr. Abel and Mr. Cristiano are no longer with us, but they definitely changed the world in which we live.

But I would also like to recall two young persons affected by leprosy who taught me the risks of reducing leprosy's experience to epidemiological goals and indicators. One is a young Brazilian woman who was living in Portugal when I first met her. She struggled for years in the Portuguese public health system to receive a diagnosis of leprosy. Health professionals simply didn't believe her and kept on treating her for other medical conditions. She was finally diagnosed with leprosy and started



“Another great man who transformed my worldview”: the late Cristiano Torres, who had “a fighting and joyful spirit that wasn't weakened by hardship.” (Photo: MORHAN)



MORHAN in action: the involvement of persons affected by leprosy in decision making is crucial for achieving sustainable inclusion, says Cruz.

on treatment only after severe disability had set in. She spent years being treated for leprosy reactions and ended up taking thalidomide. She knew she had leprosy, but since she was living in a country where leprosy was archived as a disease of the past, she was denied treatment.

The last person I would like to recall is a young Brazilian man who struggled for years with leprosy reactions. He grew up in a township and had an extremely low level of education. As such, his income was dependent on manual work, which he could no longer perform due to nerve damage and pain. He ended up stealing and going to jail, where he contracted tuberculosis. Before that, he applied several times for social benefits aimed at disability. As he showed no visible signs of disability, however, he was turned down. He used to say to me that for him there never was a cure, revealing the gap between curing and healing.

These two young persons' experiences demand from us all to look at leprosy, not as a sort of residue from the past, but as a contemporary disease that requires contemporary state and social responses.

Site visits will be an important part of your role. What countries do you intend to visit, and why?

There will be different stages and goals regarding country visits. As a first stage, I believe it is important to concentrate on those countries that still have a high incidence of leprosy—India, Brazil and Indonesia. These countries also play an important role in their respective regions. This means we can expect these visits to have a positive effect in Asia, South America and the Pacific region in terms of awareness and enforcement of human rights with regard to leprosy.

However, there are countries that, while not having a high prevalence of leprosy, still present institutional discrimination as well as extra-institutional discrimination in communities and/or

clinical settings. For that same reason, they must also be a priority. Most of those countries are located in the Asia-Pacific and Africa.

There should also be country visits with the purpose of identifying and disseminating good practices. One example would be Japan. Finally, I would like to include at least one country that, having eradicated leprosy in the past, is currently facing an increase in foreign-born cases. That would be necessary to call attention to what is becoming a difficult yet important issue concerning leprosy for which adequate state responses are lacking.

In your opinion, how important are grassroots efforts, particularly by organizations of people affected by leprosy, to eliminating stigma and discrimination?

The disability movement established a fundamental difference between organizations *for* persons with disabilities and organizations *of* persons with disabilities. This distinction was a huge step in rights-claiming. It strengthened the identity of persons with disabilities in a positive way as social agents with a voice of their own, and flattened the social representation of persons with disabilities as subjects for others' compassion.

Grassroots organizations of persons affected by leprosy play a crucial role in eliminating stigma and discrimination. First, they promote a positive identity among persons affected by leprosy and, consequently, boost their self-esteem. With a positive identity, people start making changes to their surroundings, and they tend to make them in an effective way. That is a major contribution toward rights and dignity awareness, as well as toward changing public perceptions of the disease.

Second, grassroots organizations have a privileged access to facts. They develop, although most times unintentionally, what is called popular epidemiology. By being close to communities, grassroots organizations know first-hand the difficulties and needs of persons affected by leprosy, which are many times invisible in state surveys. They are, as such, experts on health and equality data; and they also act quickly in response to urgent needs.

Third, it is well accepted nowadays that the state refers not only to its institutionalized apparatus, but also to civil society. As such, grassroots organizations are a main actor in the structural changes that fall under the role of the state as the organizer of collective life.

For all these reasons, it is highly beneficial to include grassroots organizations of persons affected by leprosy in the design, monitoring and evaluation of public policies aimed at eliminating stigma and discrimination attached to leprosy. ■

Return to Indonesia

The Goodwill Ambassador's travels take him to North Sulawesi and North Maluku provinces to promote leprosy awareness and witness encouraging examples of cooperation between local government bodies and groups of persons affected by leprosy.

INDONESIA (July 23-30)

Indonesia reports the third highest number of cases of leprosy after India and Brazil. This year and next, I am making a number of visits to observe its anti-leprosy activities and to encourage all involved in these efforts.

In July, I traveled to North Sulawesi and North Maluku provinces. They are among the 12 out of Indonesia's 34 provinces that have yet to eliminate leprosy as a public health problem.

Manado, the capital of North Sulawesi, is a three-hour flight from Jakarta. There, I called on Governor Olly Dondokambey at his residence. We had a very positive discussion, during which I mentioned *The New Atlas of Leprosy*, a guide to assist health workers in making a diagnosis. The governor expressed interest in producing a booklet aimed at the community in general, designed to raise awareness of leprosy and help reduce discrimination.

Following my meeting with the governor, I met with around 20 members of an organization of people affected by leprosy called Toumotou. Their leader Fernandez said they visit patients to offer advice, giving them the benefit of their own experience. They also liaise with government officials on improving the living circumstances of patients and people affected. I was impressed by their initiative and told them I hoped their activities would spread throughout Indonesia.

Early detection is crucial to successfully tackling



Greeting local residents who had come for a checkup at Maelang health center in Bolaang Mongondow regency in North Sulawesi Province

leprosy. Next I was taken to an area about an hour's drive from Manado to learn about a community health initiative where this is happening. About 40 people, including teachers and other influential community figures, had gathered to meet me. This is an area where people have been ostracized once it is known they have leprosy, making it difficult to come forward for treatment. Now, local influencers are promoting a correct understanding of the disease and the importance of early detection, and the initiative appears to be having an effect.

North Sulawesi is divided into regencies. My next appointment was with Regent Yasti S. Mokoagow of Bolaang Mongondow, regency health officials and others. The regencies actually carry out the work of administering healthcare, so this was an important opportunity to promote the need to raise awareness and ensure that the public is getting correct information about leprosy.

Afterward, accompanied by the regent, I visited Maelang health center where a skincare checkup had been organized to screen for new cases of leprosy.



Calling on Governor Olly Dondokambey



With Regent Yasti S. Mokoagow



With members of people's organization Toumotou in Manado

The event drew some 100 to 150 people from Maelang and surrounding communities.

Six new cases were detected as a result and I commended the regent on this case-finding initiative. I noted that the health center was stocked with supplies of MDT, so there would be no delay in starting treatment once the diagnosis was confirmed.

I told those present that leprosy is a curable disease, treatment is free and that detecting the disease early is very important. But a few people told me that a diagnosis of leprosy leads to severe discrimination, making it difficult to go to the hospital. Hearing this, I once again stressed to the regent the importance of working to end the stigma surrounding the disease.

The next day I flew from Manado to Ternate, the biggest city in North Maluku Province. I had come to see the activities of Sorofo Self-Care Group. Members of the group, who are all persons affected by leprosy, live together and look after each other. They began their activities in 2010 and currently have 24 members. Self-care groups are found in many parts of the world; what is special about this group is that they farm, run businesses, and are earning some of the funds they need to support themselves.

Moreover, they appear to be doing a very good job of taking care of each other, as there was nobody who could not get around. It was testament to how well the group was running and shows what it is possible to achieve when people come together for a mutually beneficial purpose,

The final item on my agenda was a visit to Morotai Island, part of the Maluku Islands. It has a population of around 50,000. At the government building, around 100 people—village leaders, health officials and volunteers—had gathered for a study meeting on early case detection.

Separately, it had been arranged for me to meet with persons affected by leprosy; instead, I took the decision to have them accompany me to the

meeting. I greeted them warmly in front of all present and made a point of taking each by the hand. I wanted to show by this gesture that leprosy is not be feared and that society must reach out to those affected by the disease. I have always believed in the maxim that a picture is worth a thousand words, and I certainly believe it is the case at such times.

As I was reminded on this visit to Indonesia, the geography of the country—a sprawling archipelago of over 18,000 islands—poses challenges for the uniform application of the central government's anti-leprosy strategy. In addition, decentralization gives the provinces a substantial degree of autonomy and influences how measures are applied. With that in mind, I plan further visits to provinces where many cases of leprosy still occur, in order to gauge the progress being made and what still needs to be done. ■



Attending screening in Maelang



Sorofo SCG's chairman, Asnawi Jepi



Supplies of multidrug therapy at Maelang health center

Global Leprosy Update 2016

The latest figures on leprosy reported to the WHO show the challenges that remain.

More countries than ever are providing data to the WHO on leprosy, the latest *Global leprosy update* revealed in September. A total of 143 countries reported 214,783 new cases of the disease in 2016, up from 211,793 cases reported by 136 countries in 2015.

India, Brazil and Indonesia continue to account for the most new cases. They are among a total of 22 countries that have been identified as “global priority countries” responsible for over 95% of annual new cases worldwide.

While a marginal increase in the absolute number of new cases was seen in 2016—attributed to active case-finding and improved reporting and data collection—there has been a reduction of about 3% annually in the rate of newly detected cases over the past 10 years.

However, the report noted that the proportion

of child cases and multibacillary cases of leprosy has remained at almost the same level as in previous years in most countries and at regional and global levels, indicating continued transmission. Over 18,000 children were among new cases reported in 2016.

“The global leprosy situation highlights the need for national programs to focus on issues such as sustaining political commitment, working toward universal health coverage to reach population groups at risk, intensifying early case detection activities and strengthening partnerships with non-governmental organizations and networks of persons affected by leprosy,” the report said.

“In addition to continuing to administer MDT to patients,” it concluded, “new preventive approaches such as chemoprophylaxis and immunoprophylaxis need to be considered to break the transmission of the disease.”

INDIA LEPROSY CONFERENCE

A National Leprosy Conference will be held in New Delhi from December 5 to 7, 2017.

The objective of the conference is to showcase the innovative steps being taken to eliminate leprosy from India and explore other measures that could be adopted to ensure successful achievement of the target in the coming years. It will also highlight the commitment of the Indian government in tackling the disease.

Participants from both India and overseas will include scientists, academicians, sociologists, field workers, and representatives from government health systems and partner organizations, including the WHO, International Federation of Anti-Leprosy Organizations, Association of People Affected by Leprosy and NGOs. For more information visit the conference website: www.leprosyconference.com. ■



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FROM THE EDITOR

NEW TOOLS NEEDED

“The last mile is the hardest.” “On a journey of 100 miles, 99 miles is only half way.” Readers of this newsletter will be familiar with these aphorisms as they apply to efforts to achieve a world without leprosy. They are on our lips again as we peruse the annual *Global leprosy update* from the WHO. While progress is being made, case-detection activities are being scaled up and the gap between hidden cases and detected cases has reduced, more is required.

“With the current tools, the decline will continue—though slowly,” said Dr. Erwin Cooreman, team leader of WHO’s Global Leprosy Programme, on a recent visit to Tokyo. “We need new tools if we want to make a big dent in leprosy.”

To accelerate progress, effective tools for diagnosing infection with *M. leprae* (better still, for diagnosing infection that will lead to disease) and preventive treatments or vaccines are necessary. This will require

substantial investment in basic research. Without new tools, cases of leprosy will continue to occur well into the next century at the current rate of decline.

But given that leprosy is a slow-moving bacterial infection, research will take time before meaningful conclusions can be reached regarding the effectiveness of new interventions. “That is the nature of leprosy. We cannot change the behavior the bacillus,” said Dr. Cooreman. The sooner we introduce new tools, however, the quicker we can make strides toward completing that 100-mile journey.

Regular readers of this newsletter will also know that this publication normally appears every two months. Please note that the current issue, #87 (October 2017), follows Issue #86 (June 2017). We thank you for your forbearance.