

FOR THE Elimination OF Leprosy

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



Traveling man: the Goodwill Ambassador shares a joke with two residents of a leprosarium in Krantau, Uzbekistan during a visit in 2013.

MESSAGE

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My Journey Continues

I started this newsletter in April 2003 to share information about the fight against leprosy. This marks the 100th issue. Over the years I have reported my views on leprosy elimination and activities taking place around the world. As I write, we are in the grip of the COVID-19 pandemic. I commend the efforts of medical personnel and hope the outbreak will be contained as quickly as possible.

As Goodwill Ambassador I have attached particular importance to three points: going to see where the problems lie for myself; disseminating correct information about the disease through the media; and calling on leaders to commit to leprosy control.

My motto is “knowledge and practice go together.” I believe that seeing the situation for myself is what leads more directly to solutions. I have made a point of traveling to remote areas not visited by experts in the belief my words will be more persuasive and catch people’s attention.

I have met with 458 current and former presidents and prime ministers to discuss leprosy and seek their cooperation. Compared with malaria, tuberculosis or HIV/AIDS, there are far fewer leprosy

cases. Unless you regularly engage with the person at the top, chances are the leprosy budget will be cut.

Encounters with persons affected by leprosy who have found the strength to overcome unimaginable circumstances have left a lasting impression on me. In many countries, they are becoming increasingly vocal and organized. Their voices carry more weight than anything I might say and they have a crucial role in advancing efforts against the disease.

I have worked with governments on eliminating leprosy as a public health problem. But achieving ‘elimination’ was only a milestone. Now there is the goal of “Zero Leprosy”. Many people have asked me if this is possible. I answer by saying what’s important is to keep moving toward it.

My dream is for an inclusive society—one in which not only persons affected by leprosy but all vulnerable groups have a place. Hence my journey continues. Zero leprosy and zero discrimination may not be achieved in my lifetime, but I will do my best to help us get there.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Our Goal Is Not Yet in Sight

But what matters is that we keep moving toward it, says Goodwill Ambassador.

Beginning when he was appointed Special Ambassador to the Global Alliance for the Elimination of Leprosy in 2001 and subsequently Goodwill Ambassador for Leprosy Elimination in 2004, Yohei Sasakawa has traveled the world raising awareness of leprosy. But as chairman of The Nippon Foundation, which has supported the WHO's Global Leprosy Programme since 1975, his commitment to leprosy goes back even further. To mark the 100th issue of his newsletter, we invited the Goodwill Ambassador to share his thoughts on advocacy, the empowerment of persons affected by leprosy, dealing with world leaders and what drives him on.

We are in the midst of the coronavirus pandemic. What should we be doing?

There is only so much we can do at a time like this. But it's an opportunity to take stock and plan ahead. The important thing is to stay motivated and be ready to play an active role again when the situation returns to normal. However, we need to cooperate to ensure that persons affected by leprosy are still able to receive treatment and maintain their livelihoods to the extent possible, even during the pandemic.

In Japan, there is a saying that knowledge comes only through practice.

You're now 81. You spend several months of the year traveling overseas, often to remote areas. Any thoughts of slowing down?

Is it appropriate to judge someone by their age? There are people in their 20s and 30s who don't act young. Physically, I am 81; but mentally, I feel like a youth. I still have hopes and dreams, and my passion for leprosy work remains undiminished while I still have a mission to complete. So, if I add my physical age to my mental age and divide by two, I'd say I'm still reasonably young.



Drawing attention to leprosy as a human rights issue: Yohei Sasakawa addresses the 60th session of the UN Human Rights Commission, March 2004

What impact has this work had on your life?

I have only one life and deciding what I should accomplish with it stems from an unforgettable experience I had in my younger days, accompanying my father to a leprosy hospital in South Korea. Seeing him tour the wards, hugging each patient, encouraging them and telling them to have hope, that's when I thought that I should take up this work and carry on from my father. It was a gut feeling. Just how big an influence it has been on my life, and how much I have been enriched, is something I am now appreciating.

You often say that the solutions are found alongside the problems, and frequently travel to the field. Can you share any examples where this has made a difference?

In Japan, there is a saying that knowledge comes only through practice and that a true leader acts on his words. Hence while I respect reports, I don't rely on them alone. I want to see the situation with my own eyes.

For example, when we decided to fund the free distribution of multidrug therapy (MDT) around the world for five years from 1995, I felt it was necessary to check that it was reaching the patients. Thankfully, in most cases it was. But in some countries, the drugs only reached as far as the health ministry and sometimes not even that far. So, there were frequent occasions when I had to point this out and make sure MDT was delivered to the patients.

Part of your work as Goodwill Ambassador involves high-level advocacy. You are often seen with world leaders. Do you know how many you have met?

Fortunately, my secretary keeps a record. In terms of current or former presidents and prime ministers, I'm told the number comes to 458. If you include health ministers and other ministers, deputy ministers, governors and such, then it runs into thousands. But bear in mind that I was already doing this in my role with The Nippon Foundation, long before I became Goodwill Ambassador. I have made a total of 909 trips abroad for leprosy, totaling 3,354 days; the total number of countries visited is 121. In other words, I have spent around 10 years outside Japan on this work. All of which is to say, I don't think anyone else has traveled abroad to this extent for leprosy.

What does it take to get government leaders interested in and committed to doing more for leprosy?

First you have to explain the misunderstandings that surround the disease and the tragedies this has led to. Leprosy has been around since the days of the Old Testament and, in my opinion, is the first example

VOICES

"Being cured of the disease alone does not restore normal socio-economic status to those affected. Fear and wrong notions about leprosy still prevail in the minds of people. As a result, discrimination of people affected by leprosy still continues in many ways."
—P.K. Gopal (India), Issue #4 (October 2003)

"Anytime anyone is diagnosed with this disease, they are traumatized because they are burdened with 3,000 years of stigma, fear and rejection."
—Bernard K. Punikai'a (USA), Issue #11 (December 2004)

"If you are found to have a leprosy patch, people believe you have only been created to beg."
—Alhaji Shehu Sarkin Fada (Nigeria), Issue #13 (April 2005)

"I did not get the bag and shawl that were given to all delegates as I was late arriving, but what I got today was something I never got in the last 30 years since I had leprosy: respect and dignity."
—Participant in first national assembly of persons affected by leprosy, India, December 2005, Issue #18 (February 2006)

VOICES

“A very important thing for us is to be united, because without unity we cannot achieve anything substantial, in spite of the good wishes of many others.”

—Bhimarao Madhale, Issue#18 (February 2006)

“I keep my asking myself why we can't live normally like other people and enjoy the same treatment and equal rights. But I realize that day will come only when more attention is paid to our rights and the public has a better understanding of leprosy.”

—Liu Zhen Xi (China), Issue #36 (February 2009)

“You can do anything. But you must have confidence —with confidence you can conquer the world. No tears, no fearing.” K.N. Madhavachari (India), Issue #42 (February 2010)

“It was the public that in the past allowed the government to isolate us. Thereafter, society completely forgot about us and took no interest in the matter. It was because no-one raised their voices that we remained in isolation for so long.”

—Michihiro Koh (Japan), Issue #45 (August 2010)



Heading in the right direction: astride a mockup of the leprosy “motorcycle”

of people discriminating against other people on the grounds of disease. Since the Middle Ages and into the modern era, it has mostly affected the poor. They have been ostracized by society because of their illness and their human rights trampled on.

There is a lot of ignorance concerning leprosy. I've had leaders tell me that it was only because of my visit that they became aware that leprosy existed in their country. That's why I make these visits—to create awareness. When I meet with a leader, the health minister and other relevant ministers are usually present. If a country's chief executive gives assurances about leprosy and a budget is allocated, then the health ministry has to act. In any country battling diseases such as HIV, malaria and TB, a disease with a comparatively small number of cases such as leprosy is at the bottom of its list of priorities. To change that, it is necessary to persuade the people at the top.

You have long championed the empowerment of persons affected by leprosy and invite them to accompany you when you meet with political leaders. How do you see their role?

You will have heard me talk about leprosy in terms of a motorcycle. The front wheel represents curing the disease and the rear wheel represents restoring human rights. In other words, we need to eliminate the discrimination as well as the disease to realize a society in which people can live normally. For thousands of years, people affected by leprosy have been oppressed by society due to misconceptions and lack of knowledge about the disease. They still face discrimination, even now leprosy is curable.

By approaching the international community about this I think I was able to create an opportunity for leprosy to be taken up as a human rights issue. Eventually this led 193 countries to unanimously adopt a resolution on elimination of discrimination against persons affected by leprosy and their family members at the UN General Assembly in December 2010, accompanied by Principles and Guidelines.

Discriminatory laws and attitudes remain, however. For that to change, persons affected by leprosy must speak out, as they are the ones impacted by this. They are entitled to live in dignity, earn a living and contribute to society—which can include helping to identify new cases of the disease. I am always telling them: ‘Join together, speak out and make your voices heard.’

So, what I am saying is, it is important to focus on solving the social problem of discrimination at the same time as tackling the medical issue of leprosy. When both wheels of the motorcycle are turning at the same time, then we are heading in the direction of a real solution. I've always wanted to lead the way on that.

What's needed to bring about social change?

You can't move people with conferences and papers alone. The way they think is influenced by their surroundings and how they live, and each country has its history and culture. Even couples may have different ideas about leprosy. That's why it's important to communicate correct information about the disease and work steadily to fix discriminatory laws and regulations. You just have to keep at it.

At the time of the Beijing Olympics, persons affected by leprosy were going to be barred



Calling on Prime Minister Meles Zenawi of Ethiopia, accompanied by Birke Nigatu, chairman of the Ethiopian National Association of Ex-Leprosy Patients, February 2006



Taking part in a Sparsh leprosy awareness campaign in Jharkhand, India, 2018

from entering China. For my part, I wrote to the International Olympic Committee as well as the Chinese leadership and the mayor of Beijing, and in two weeks the matter was resolved.

I have also had occasion to write to Pope Francis, who has 1.2 billion followers worldwide, following a number of unfortunate statements on his part. I conveyed to him that leprosy is a curable disease; it is not hereditary, nor is it a divine punishment, so please do not use it as a metaphor for something bad. Subsequently there was an international symposium on Hansen's disease at the Vatican, co-sponsored by The Nippon Foundation, which conveyed these points to the Catholic faithful.

I've had leaders tell me my visit made them aware of leprosy in their country.

What's necessary is for everyone to keep speaking out about the issues. Discussing something in an air-conditioned room and writing a report doesn't solve anything. It's important to get people involved, go and see the situation for oneself, and talk to as many people as possible.

What encounters have made the biggest impression on you?

It's the ones with people who have overcome the disease and are living strongly. But many others still lead very difficult lives. Existing on the margins of society, some believe that begging is the only way of life open to them because of leprosy.

I think of a man I met on Biwak Island

in Indonesia, who was abandoned by his relatives and lived alone. They brought him food from time to time, but on days when they didn't, he just stayed in his hut and went hungry. Or a man in India living in isolation on the edge of a village; he had a wife, who brought him food, but he couldn't live with her because the villagers wouldn't allow it. There are still many people like this in the world that we don't know about. It weighs heavily on me that we can't find them all. We have to do more.

The term 'elimination' has attracted criticism over the years for giving the impression that leprosy has disappeared after countries announced they have 'eliminated' leprosy.

What do you say to that?

The elimination target was "elimination as a public health problem" or a prevalence of less than one case per 10,000 population. It was only ever a milestone, not the end goal. But it is true that "as a public health problem" has tended to be forgotten. That said, it is not enough just to say, "Let's all work together to get rid of this disease." There needs to be a specific numerical target for everyone to pursue together. That's why I welcome the fact that we have a new goal, which is "Zero Leprosy."

You have already mentioned the motorcycle. Is the destination in sight?

We're not there yet. What matters is to keep heading toward it, not how far away it is. In a tunnel, if you keep going you will eventually reach the other end. In that sense, I think it's more important to work together in the same direction to achieve our goal,



Meeting a man abandoned by his family on a visit to Biwak Island, Indonesia, in 2014. Subsequently, the man was able to resume his life as a fisherman.

VOICES

"As a person affected by leprosy, I feel compassion for others like me. I refuse to accept they must suffer the kind of discrimination I suffered at the hands of my family and society."

—Muslim Momin (Nepal), Issue #51 (August 2011)

"Our children are healthy, but society does not accept them. People say it's nice that leprosy is curable, but they are not ready to integrate with people who have had the disease."

—Vagavathali Narsappa (India), Issue #52 (October 2011)

"For me, Hansen's disease is not only a physical condition. There are psychological factors at work that can cause the lesions and after effects to become more severe."

—Jose Tadeu Bezerra de Oliveira (Brazil), Issue #53 (December 2011)

"Even though you may be medically cured, you still have the disease as long as there is stigma and discrimination."

—Alem Galeta (Ethiopia), Issue #71 (December 2014)

VOICES

“As people affected by leprosy, we have had to fight for the right just to enjoy a normal life.”

—Kimie Yamauchi (Japan), Issue #72 (February 2015)

“Among the many suggestions was to preserve our history. We wanted future generations to know that we lived with dignity and pride, despite all forms of discrimination. We wanted our legacy to give them hope.”

—Yasuji Hirasawa (Japan), Issue #79 (April 2016)

“My mother believed that God was punishing her through me.”

—Jose Ramirez, Jr. (USA), Issue #81 (August 2016)

“Even as an informed person, I had to confront the age-old image we have of leprosy as some kind of punishment: what had I done wrong in my life to deserve the disease?”

—Evelyne Leandro (Brazil), Issue #86 (June 2017)



“Join together, speak out and make your voices heard”: scene from India’s first-ever national conference of persons affected by leprosy, New Delhi, December 2005, held under the theme of “Integration and Empowerment”

rather than calculating the remaining distance.

Take India, where the prime minister has set a goal of zero leprosy cases by 2030 and has shown a strong commitment to vanquishing leprosy. Experts question whether this is possible by 2030. I would argue that what is important is to make progress toward this goal. The results will follow.

What’s needed is for all of us to be moving in the same direction.

It’s the same when talking about discrimination and how to resolve it. It’s a problem in people’s minds. Perspectives, impressions and prejudices about leprosy vary from person to person. What’s needed is for all of us to be moving in the same direction.

What else should we be thinking about as we go forward?

We need to create as many allies as we can. It’s an unfortunate fact, but the world just tends to follow trends. When the environment became a hot topic, 12,000 gathered in Rio de Janeiro for the Earth Summit in 1992. Of course, the environment remains an important issue, and is still being debated, but not with the energy we saw back then. Now we have coronavirus—a problem some might say is as big as the plague was for humanity.

As new challenges emerge, one after another, it’s

easy to forget issues like leprosy, where the actual numbers are small. But when it comes to the gravity of the discrimination that persons affected by leprosy face, I find it totally unacceptable that human beings—the only living creatures blessed with reason—are capable of such irrational behavior. In that sense, leprosy carries a lot of symbolic weight and resolving the issues surrounding it should be of paramount importance to humanity.

Did you think that the “last mile” in leprosy would take this long?

I don’t know that this will end in my lifetime. I will continue to fight against the disease, and the stigma and discrimination persons affected by leprosy still face, to the extent that I can. But if there are still issues remaining, then I want to find a way for the next generation to take them on. ■



Attending a branch meeting of the Movement for the Reintegration of Persons Affected by Hansen’s Disease (MORHAN), Pernambuco, Brazil, 2015

2003

WHO Special Ambassador's Newsletter launched.



2004

Yohei Sasakawa appointed WHO Goodwill Ambassador for Leprosy Elimination.



2007

Brazil's president authorizes payment of lifetime monthly pension to persons affected by Hansen's disease forced to live in hospital-colonies.

Yohei Sasakawa appointed Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy.

National Hansen's Disease Museum established in Japan, expanding existing Prince Takamatsu Memorial Hansen's Disease Museum.



2003

2004

2005

2006

2007

2008

Efforts begin to have leprosy discrimination taken up as a human rights issue at the global level.

2003

Yohei Sasakawa visits Office of UN High Commissioner for Human Rights to raise leprosy as human rights issue, the start of repeated visits to Geneva.



2006

Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy launched. The annual appeal is now in its 15th year.

Culion, Philippines marks centenary of founding of former Culion Leper Colony, at one time the world's largest leprosy settlement and a center of research. Celebrates transformation from island of despair to island of hope.

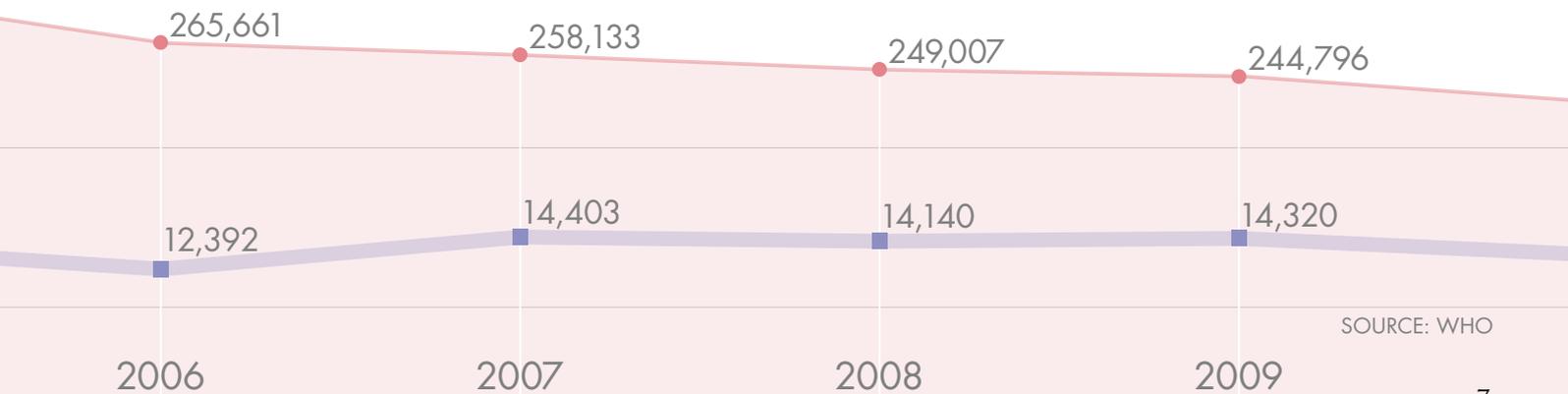


2008

17th International Leprosy Congress, Hyderabad, India



Discovery of a new leprosy-causing bacterium, *Mycobacterium lepromatosis*, very similar microbiologically to *Mycobacterium leprae* discovered by the Norwegian Armauer Hansen in 1874.



SOURCE: WHO

2009

Father Damien of Molokai is canonized.

2010

UN General Assembly adopts resolution on elimination of discrimination against persons affected by leprosy and their family members. Follows three earlier resolutions at Human Rights Council between 2008 and 2010.



2013

International Leprosy Summit, Bangkok, Thailand, issues "Bangkok Declaration: Toward a leprosy-free world". The Nippon Foundation establishes Bangkok Declaration Special Fund for innovative approaches to case finding.



18th International Leprosy Congress, Brussels, Belgium ("Hidden Challenges")

2016

19th International Leprosy Congress, Beijing, China ("Unfinished business: stopping transmission, preventing disability, promoting inclusion")



2009 > > 2010 > > 2011 > > 2012 > > 2013 > > 2014 > >

Workshops and symposiums call for the preservation of leprosy history and heritage as an asset to humanity.

2011

WHO Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services. An empowering document that no longer casts persons affected exclusively in the role of recipients of services but recognizes what they can contribute in areas such as advocacy, awareness and rehabilitation.

2012

London Declaration on Neglected Tropical Diseases (NTDs). A collective public and private-sector promise to control or eliminate 10 NTDs, including leprosy, by 2020.

International Workshop on the Preservation of Hansen's Disease/Leprosy History and Heritage, Tokyo, Japan. The first of five workshops and symposiums held between 2012 and 2017, prompted by the need to act before records, sites and memories disappear, and the conviction that this history contains valuable lessons for future generations.

2014

His Holiness 14th Dalai Lama accompanies Goodwill Ambassador on visit to Tahirpur Leprosy Colony, Delhi, India, telling residents: "Everybody has an equal right to happiness."



2016

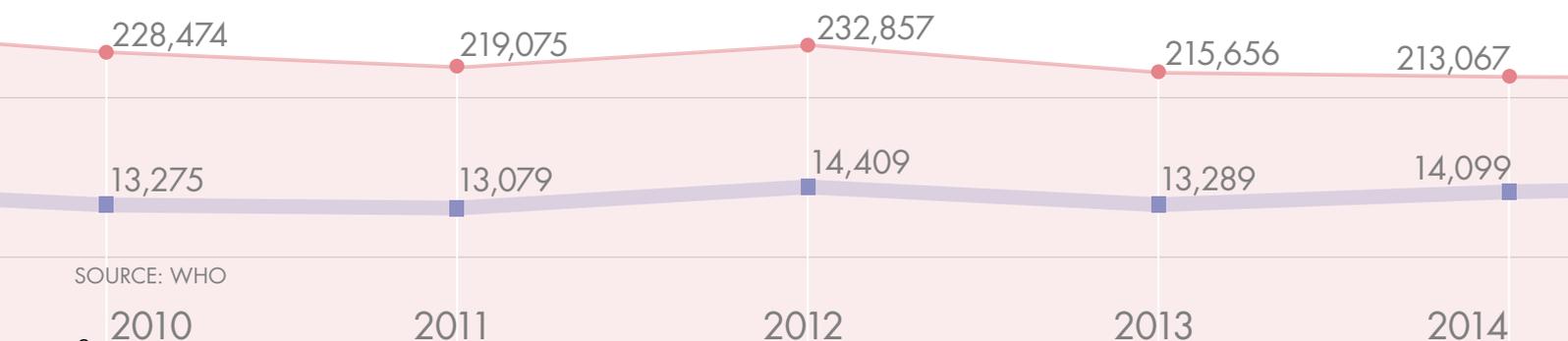
WHO Global Leprosy Strategy 2016-2020: Accelerating towards a leprosy-free world. Targets zero disability in children and reducing new cases with disability to less than 1 per million population, and incorporates interventions against stigma and discrimination.

International symposium "Toward Holistic Care for People with Hansen's Disease, Respectful of Their Dignity", Vatican City. Calls on religious leaders to use influence to promote awareness of leprosy, end use of terminology that reinforces stigma.



2016

International Leprosy Association—History of Leprosy website launched, building on ILA's Global Project on the History of Leprosy of 2001 to 2007.



SOURCE: WHO



2017

UN Human Rights Council appoints Special Rapporteur on elimination of discrimination against persons affected by leprosy and their family members for a three-year term.



2018

WHO Guidelines for the Diagnosis, Treatment and Prevention of Leprosy. For the first time, the WHO recommends chemoprophylaxis (single-dose rifampicin) under certain circumstances as a preventive treatment for contacts of patients.

2019

Yohei Sasakawa receives 2018 Gandhi Peace Award from Indian government.



Japanese district court orders government to compensate family members of leprosy patients for discrimination they also suffered as a result of past government policies.

>> 2015 >>> 2016 >>> 2017 >>> 2018 >>> 2019 >>> 2020 >>>

A new global partnership emerges, aiming at no disease, no disability, no discrimination and no stigma.

2018

Global Partnership for Zero Leprosy launched to accelerate collaborative action toward the goal of ending leprosy.



2019

Global Forum of People's Organizations on Hansen's Disease, Manila, Philippines. Participants underscore that Hansen's disease is not just a health issue but an issue of human rights.



20th International Leprosy Congress, Manila, Philippines ("Global Partnership in Addressing Current Challenges")

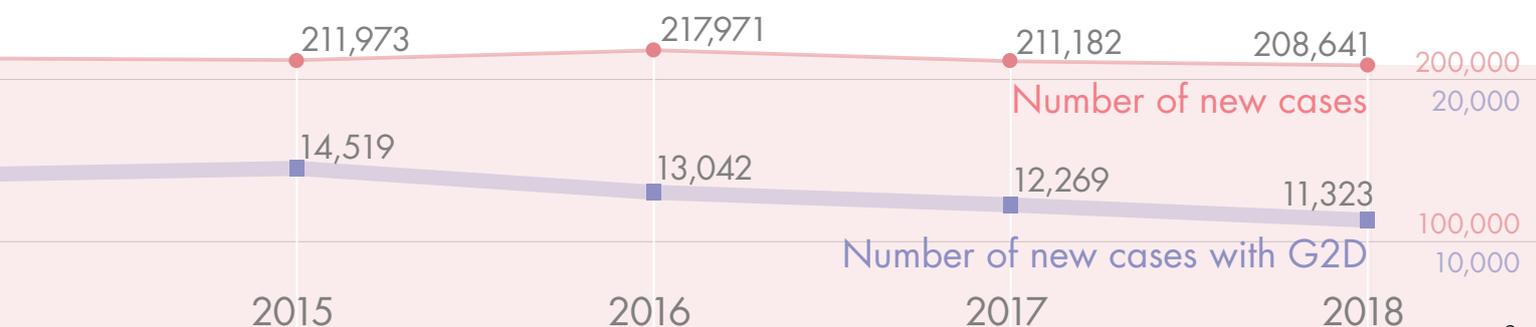
2020

World Hansen's Disease Day Joint Action by 17 organizations of persons affected by Hansen's disease from 16 countries, using common logo and slogan: "Hansen's Disease Free World with Knowledge and Love."



Launch of WHO Neglected Tropical Diseases Roadmap 2030 (June). For leprosy, global targets include: (1) annual new cases 62,500; (2) G2D rate 0.12 per million population; and (3) rate of new pediatric cases 0.77 per million children.

100th issue of Goodwill Ambassador's Newsletter published.



Encouraging Signs

UN Special Rapporteur on leprosy reflects on three years in the role.

A notable milestone in the years since this newsletter was first published was the 2010 UN General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members. This has resulted in a growing focus on leprosy as a human rights issue and paved the way for the appointment in 2017 of a UN Special Rapporteur on leprosy for a three-year term.

In February, Alice Cruz made an official visit to Japan, during which she called on the Center for Human Rights Education and Training. There she was interviewed by its president, Professor Shigeaki Sakamoto, who oversaw the Principles and Guidelines that accompanied the 2010 resolution, and its managing director, Tatsuya Tanami, special advisor to The Nippon Foundation and former executive editor of this newsletter. Excerpts from the interview, which appears in Japanese in the Center's publication *Allyu*, are used with permission.*

What is a UN Special Rapporteur?

A Special Rapporteur is an independent expert, usually with some sort of background experience on the theme of their mandate. For that reason, they are able to make quick assessments of the situation in a given country and are also expected to provide technical support to improve a country's actions. Our method of working is to present reports to the Human Rights Council. These can be thematic reports or country reports. I think that one of our main missions is to give a voice to the voiceless—to act as a bridge between governments and the UN system, and people on the ground.

What kind of discriminatory attitudes, practices, customs and regulations do persons affected by leprosy/Hansen's disease face?

The situation is very different from country to country. There are countries where there are still a fairly high number of new cases, together with all the issues that people living with Hansen's disease face, such as discrimination and disability, and other countries where Hansen's disease is no longer significant from an epidemiological standpoint, but where stigmatization persists.

There are countries that still have a number of discriminatory laws—India alone has more than 100—and countries that still have a lot of discriminatory institutional practices. I'm particularly worried about what can be a new type of human rights violation, which I call institutional neglect. I hear from many persons affected, especially in African countries, who feel that the numbers reported by their governments are not accurate. I worry that in some countries, Hansen's disease can be completely neglected because it is not one of their priorities. That can favor transmission, but also ongoing discrimination.



Alice Cruz (left) with Professor Shigeaki Sakamoto in Tokyo

What has been the reaction of member states of the Human Rights Council to your work?

The first time I presented to the Council, there were some states saying this mandate should not exist because it overlaps with other mandates, such as health or disability. But I believe that with the work of the mandate, and especially with the most recent thematic report**, which was very descriptive, the attitude of the Council changed and I received a lot of support. The strategy to try to gather information about people's experiences of discrimination worked very well. Because the report gave voice to the people, member states realized that people are suffering multiple violations and that this is truly a human rights issue.

You talked about institutional discrimination. Have you found other factors that influence attitudes toward people affected by leprosy, such as religious or other long-held beliefs?

I think what is striking about Hansen's disease is that we find a stigmatizing response to it from almost every religion, which itself is striking because we are talking about very different cultural backdrops. For example, religions have historically represented leprosy as the opposite of morality. In Christianity, we have the association between leprosy and sin, while in Buddhism it is associated with reincarnation and bad deeds in a past life. There is always this notion that somehow people affected by leprosy are responsible in some way, so they deserve punishment. They incorporate everything that society sees as bad.

What I found most striking about last year's research from my report is that the stereotypes that endure in religious beliefs and social beliefs do not affect everybody the same way. Women usually are very much more vulnerable to these types of religious stereotypes on leprosy. We cannot separate that from gender equality, and must try to work on that too. I think it is very much interlinked.

VOICES

"If you are diagnosed with leprosy, please take your medication regularly and follow the advice of your doctor. Keep your spirits up!"
—Al Qadri (Indonesia), Issue #88 (December 2017)

"If you want to change discrimination, you have to change the way we speak about the disease."
—Faustino Pinto (Brazil), Issue #89 (February 2018)

"What was the happiest time in your life?" "My youth, because it was joyful."
"And the saddest time?" "My youth, because it was destroyed by leprosy."
—Sahtreen (India), Issue #90 (April 2018)

FOOTNOTES

* Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

** "Stigmatization as dehumanization: wrongful stereotyping and structural violence against women and children affected by leprosy"

*** There have been five UN Human Rights Council resolutions and one General Assembly resolution on leprosy between 2008 and 2017.

VOICES

“Leprosy is not the problem. It is lack of awareness that is the problem”

—Paulus Manek (Indonesia), Issue #90 (April 2018)

“Strengthening the participation of persons affected by leprosy is the most effective way to reduce the burden on government health departments.”

—Frank Onde (Philippines), Issue #94 (April 2019)

“If, every day, we contribute love and happiness, think how much we could change the world.”

—Lucrecia Vasquez (Colombia), Issue #94 (April 2019)

Part of your role is working on how to have countries implement the Principles and Guidelines. But what role do they play in a real sense? Where we are now?

Even though persons affected by Hansen’s disease and their families are protected by international human rights instruments, the Principles and Guidelines can provide governments with a roadmap on how to enforce already recognized rights for a very vulnerable and marginalized population. I can see that there are many initiatives that some states take that closely relate to the Principles and Guidelines. I think my task is not only to try to raise awareness of this instrument, but also to show in practical terms how it is being implemented in order to strengthen this more direct connection between what the governments are trying to do and the Principles and Guidelines. I think too that we cannot disregard the importance of this instrument for the persons affected themselves. Having had all these resolutions at the UN, and having an instrument just for them, is really empowering.*** Empowerment, from my perspective, is the key for the sustainability of the human rights approach.

I feel that the understanding of states with regard to Hansen’s disease is beginning to change.

You are now in your third year as Special Rapporteur. What do you think you have achieved, and what challenges remain?

I had great expectations when I took on this very complex role. I have learned along the way that I need to look at very small results as encouraging, because the big results keep falling from my hands; they are very difficult to reach.

For example, I would have liked to have had the opportunity of visiting more countries and of engaging more directly in a conversation with the states. What I think acted as the main barriers to this are as follows. First, this is a new mandate, and it takes time for new mandates to establish themselves within the system. Second, it is really hard for people to grasp that leprosy is a human rights issue. Even the civil society organizations working with Hansen’s disease are really just beginning to work on the issue as a human rights issue. So, not only was the UN system not prepared for this mandate but I think civil society was also not prepared—and for the mandate to be successful, both those elements are necessary.

But I think there is also another dimension, very much more deep-rooted, that relates to the stigmatization of leprosy. I feel that in the mindset of most people—and that includes people working for governments—leprosy is really something that must be left in the past, or, if it is not in the past, must be quickly thrown into the past; it is not an issue to talk about.

Can you point to any accomplishments?

Notwithstanding what I have just said, I feel that the understanding of states with regard to Hansen’s disease is beginning to change, and that may be the start of something better. We had a side event last June in Geneva and it was amazing—the reaction of not only the governments that were there, but also our senior officers of the Office of the UN High Commissioner for Human Rights. They really didn’t know or understand why leprosy is important. Their thinking was, when we are dealing with extreme poverty, with violence against women, why does leprosy matter? But once they hear the people, and they understand that they are victims of poverty, of gender-based violence, of all those issues that they work with, they see the point—they see that leprosy is really about all that.

I am happy too that I have been able to mainstream leprosy within the system. When the mandate began, the Treaty Bodies and the Universal Periodic Review were not including leprosy in their work; now all the human rights mechanisms have included leprosy one way or the other.

What have you learned from your Japan visit?

I think Japan has a very important lesson to share with the world with regard to the importance of people resisting violations perpetrated by the state, standing up and speaking out, and how that is key to truly building a democratic and free society. I think that the struggle of persons affected and family members in Japan teaches a lot about that. But I also think that it is very important to commend the government for listening to the people’s voices and respecting their choices. Both these elements are important.

Your three-year mandate concludes this year. Can you tell us what you plan for your final report?

I want to leave states, national human rights institutions, civil society organizations and intergovernmental agencies with a concrete policy framework for rights-based action plans to eliminate Hansen’s disease-related discrimination. Actually, that is the title of my last report, which will be presented to the Human Rights Council in June. ■

Leprosy and COVID-19

Efforts under way to keep essential services operating and people affected safe.

The spread of the novel coronavirus around the world has had an impact on leprosy services and communities of people affected by the disease, with active case-finding activities suspended, health workers reassigned to emergency duties and the vulnerable position of persons affected exacerbated by the COVID-19 pandemic.

NGOs have been reaching out to communities with advice, food, and hygiene and medical kits, while guidelines have been issued to ensure essential services are maintained and to inform persons affected by leprosy about what they need to do to stay safe.

“Advice about leprosy and COVID-19” issued jointly by the WHO, International Federation of Anti-Leprosy Associations (ILEP) and Global Partnership for Zero Leprosy (GPZL) has been distributed to national leprosy programs, while the Brazilian Society of Hansen’s Disease has drawn up guidelines specifically for persons affected

by leprosy. The latter call on self-care groups to suspend face-to-face activities to avoid exposing members to infection and exhorts people “to take good care of your mental health during this crisis.”

Responding to the pandemic, the GPZL has set up three working groups—Leprosy Emergency Operations, to assess the situation facing national programs and facilitate solutions to operational challenges such as maintaining drug supplies; Emergency Advocacy for Persons Affected, to gather perspectives on people’s needs in the face of the pandemic; and a Post-COVID-19 group.

Testimony gathered by the emergency advocacy group from more than 25 organizations and around 70 persons affected by leprosy worldwide highlights the difficulties faced by disadvantaged populations in adhering to recommendations for preventing COVID-19 infection when lacking access to basic amenities such as clean water and soap. ■

FROM THE EDITOR

THE LAST MILE?

In the first issue of this newsletter in April 2003, the then Special Ambassador for the Elimination of Leprosy wrote: “[I]t is said in Japan: ‘In a journey of 100 miles, the 99th mile is no better than half-way.’ The final mile is perhaps the most arduous.” One hundred issues (and many air miles) later, the same still holds.

When those words were written, the WHO’s target of eliminating leprosy as a public health problem had already been attained at the global level. Defined as a prevalence rate of less than 1 case per 10,000 population and set at the 1991 World Health Assembly, elimination as a public health problem garnered political and financial support and was achieved in 2000. By 2003, the focus was on elimination at the national level in every country by 2005.

In the end, that milestone was reached, if not by 2005, by most countries around a decade ago. That is also around the time that annual new case numbers, which had been in decline, leveled off at over 200,000 a year, where they have remained ever since.

Despite the effectiveness of multidrug therapy in treating the disease, it is proving difficult to ‘beat’ leprosy and deal with all its consequences.

There is a need to break transmission and prevent infection if we are to see further progress. In the meantime, communities of persons affected by leprosy remain socially and economically vulnerable, a fact highlighted by the current coronavirus pandemic.

Going forward, we look to new initiatives and interventions to help us progress. The Global Partnership for Zero Leprosy (GPZL), formed in 2018, is injecting fresh momentum into leprosy work. Integrating aspects of leprosy control with those of other Neglected Tropical Diseases (NTDs) provides opportunities for synergy, while the forthcoming WHO NTD Roadmap 2030 advances the definition of ‘elimination’ for leprosy as the elimination of transmission, which is the goal of the GPZL.

The direction of travel is clear, but how arduous will the journey be? Alice Cruz, the UN Special Rapporteur on elimination of discrimination against persons affected by leprosy and their family members, says in these pages that she went into the role with great expectations, but that “I have learned along the way that I need to look at very small results as encouraging.” As we continue to contemplate the ‘last mile’ in leprosy, this might be the most realistic way to approach the road ahead.

FOR THE ELIMINATION OF LEPROSY

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