

FOR THE Elimination OF Leprosy

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



Coordinated thinking: (L to R) Paulus Manek, Dr. Sigit Priohutomo, the Goodwill Ambassador and Al Kadri in Jakarta on Oct. 2 (see p.5)

MESSAGE

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Leaders' Ill-Informed Remarks

Some 16 years have passed since I first became the WHO's Goodwill Ambassador for Leprosy Elimination. During that time, I have seen and heard various influential leaders, the media, filmmakers and others use leprosy as a metaphor for something bad. In doing so, they draw on associations of the disease as something frightening, incurable and "unclean." Given that leprosy can be treated and cured, it is extremely regrettable that among world leaders are persons who make such insensitive remarks.

In June, French President Emmanuel Macron gave a speech in which he said that nationalists were rising "a bit like leprosy across Europe"; and again, in October, he decried "nationalist leprosy." Wherever possible, I write to those concerned and ask them to reflect on what they are saying.

I have sent letters to Pope Francis on several occasions when he summoned the image of leprosy to condemn some aspect of the church establishment that he found wanting, and requested that he not do so. I wrote to the IOC and the Chinese government when it seemed that persons with leprosy would be banned from entering the country at the time of the

Beijing Olympics and the issue was resolved. I also wrote to the makers of an animated film about a scene that depicted leprosy in a distorting light, and it was amended.

Recently, television commentators in the United States took to scaremongering about a "migrant caravan" as it approached the country's southern border. They claimed that it carried with it the threat of disease outbreaks, including leprosy.

Fear, misinformation and ignorance have serious repercussions. In particular, I urge those in positions of influence to choose their words with care. I invite all of you to write your own letters of protest when you encounter instances of leprosy being used in a stigmatizing way. When you do, please refer to the UN resolution on elimination of discrimination against persons affected by leprosy and their family members adopted in December 2010.

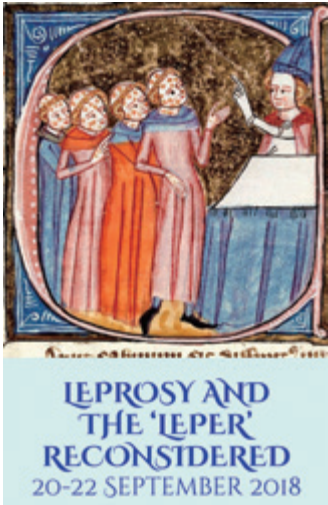
I believe that the efforts each one of us takes, as they build up over time, will lead us toward a world where leprosy is no longer misunderstood.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Erasing Boundaries

A recent conference sets leprosy history studies on an exciting new path.



Toward a more complete view: "Leprosy has been stereotyped as a paradigmatic 'medieval' disease."

In September 2018, McGill University in Montréal, Canada hosted a conference that brought together academics from a wide array of fields and time periods to begin a conversation aimed at broadening and unifying the discussion on leprosy and those affected by the disease.

Leprosy and the 'Leper' Reconsidered had its origins in the 2016 Leeds International Medieval Congress where I had co-organized, along with Dr. Elma Brenner from the Wellcome Library, a strand titled *Leprosy and Identity*. This included a paper by Courtney Krolikoski, with whom I spent the majority of the conference. One of the topics we kept circling back to was why there was no complete study about the history of leprosy. *Leprosy*

and the *'Leper' Reconsidered* was our proposed solution.

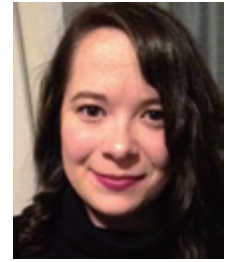
Both Courtney and I are medievalists specializing in the history of medicine and/or social welfare, with particular attention to leprosy. As such, we are acutely sensitive to the ways in which leprosy has been stereotyped as a paradigmatic 'medieval' disease, in the most sensationally negative sense of that term.

This is unfortunate in two ways. First, the new histories of medieval leprosy pioneered by François-Oliver Touati, Carole Rawcliffe and Luke Demaitre, which have overturned previous ideas about how medieval societies viewed leprosy and treated those with the disease, are often overlooked by non-specialists. Second, the inordinate focus on leprosy in the medieval West has obscured other histories of leprosy in other parts of the world, and in other eras.

That being said, the way in which both popular and academic writing discusses this illness, especially in the medieval context, is often incorrect. We knew that the only way to break down the artificial barriers that existed—not only between time periods, but also disciplines—was to host a conference.

INTERDISCIPLINARY FRAMEWORK

Fundamentally, *Leprosy and the 'Leper' Reconsidered* was conceived as a means to explore how communities around the world have approached leprosy and



AUTHOR:

Dr. Anna Peterson

Dr. Anna Peterson is a historian of medieval welfare institutions. She is currently a Mellon Fellow at the Pontifical Institute of Mediaeval Studies in Toronto, Canada working on a project titled: 'Detesting such neglect and abuse': the Church's response to corruption in hospitals and leprosariums in western Europe (c. 1200–1342).

A NEW APPROACH

"Leprosy opens more windows onto the past than any other disease," Professor Luke Demaitre remarked in his keynote address at *Leprosy and the 'Leper' Reconsidered*. This observation could be extended to argue that leprosy, or Hansen's disease, in fact opens more windows to think about discrimination and exclusion in the present as well as the past, *Kathryn M. Tanaka writes*.

In a time when U.S. news commentators evoke "leprosy" together with "smallpox, rabies, and HIV" as a menace associated with migrant populations, it is clear that the stigma persists and the disease has powerful associations with perceived threats to society today. In that sense, an interdisciplinary and global conference on the subject of Hansen's disease was long overdue.

As a scholar of Japanese literature, there were several features that I found particularly useful about this conference, which I attended to present work done for Professor Yukiko Araragi's grant project, "Polyphonic Approaches to Leprosy Problems: New Research for the 'Era of Reconciliation'."

First, I was impressed with the recurring themes brought forward by Hansen's disease that connected

disciplines as diverse as medieval European history and modern Japan cinematography. Of course, research into changing forms of discrimination and exclusion are a part of Hansen's disease research as a whole, but this conference helped highlight other, less-considered parallels.

An example would be the iconography of Hansen's disease in religious discourse. Many presenters discussed the religious significance of this in Catholic theology, and Professor Susan Burns introduced some parallels in the Buddhist traditions of Japan during her keynote lecture. Gender was another common theme of the conference, and several presenters such as Dr. Lucy Barnhouse and my own work explicitly foregrounded the gendered experience of Hansen's disease.

Furthermore, as a whole the papers represented an important shift in the study of Hansen's disease that I found particularly important and inspiring. Rather than strictly historical or theological approaches to the subject, the papers all shared an interdisciplinary approach that incorporated an element of anthropology.



Kathryn M. Tanaka

leprosy sufferers. We invited historians, scholars of art, film, archaeology, religion and literature to participate, and we also included new theoretical tools such as disability studies, and new historical techniques like digital humanities.

Our aim was to bring new clarity to questions about the human experience of leprosy.

At the same time, we did not neglect crucial medical and scientific histories of leprosy, while anthropological, archeological and material culture contexts also featured. We provided a space to examine the disease’s impact as it intersects with gender, class and race, and addressed the complex and violent history of the term ‘leper’.

Our aim was to bridge the gap between scientists and social scientists to bring new clarity to questions about the human experience of leprosy, and to open new research opportunities, modeled on the work of the historian of medicine Professor Monica Green. In 2014, Green edited *Pandemic Disease in the Medieval World: Re-thinking the Black Death* as the inaugural issue of the journal

* Monica Green (ed.), *Pandemic Disease in the Medieval World: Rethinking the Black Death*, the inaugural issue of *The Medieval Globe*, 1, No. 1 (2014).

** Helen King and Monica Green, “On the misuses of medical history,” *The Lancet* 391, no. 10128 (2018): pp. 1354-1355.

The Medieval Globe.^{*} This was the first history of Late Medieval and Early Modern plague to embrace a Eurasian perspective, and to engage on a high level with the most recent immunological and bioarchaeological research.

Green has become a vocal advocate in the professional and public media for closer integration of medical history and the science of infectious disease; this was particularly notable during the Ebola crisis, where she penned numerous essays and op-ed pieces, and created new courses for her history undergraduates to model how specialists in the past and biomedical scientists can mutually enrich their analyses.

Most recently, she co-authored an open letter with Dr. Helen King in *The Lancet*^{**} calling for scientists and physicians to consult historians as a means of creating an open dialogue between our two fields in an effort to ensure that the history in medical articles reflects the current historiographical approach.

We look forward to the second meeting of *Leprosy and the ‘Leper’ Reconsidered* because we hope to continue to foster a strong dialogue between the humanities and the sciences so that we can develop well-rounded and accessible studies in order to continue to demystify leprosy and the people who are impacted by it. ■



Conference emphasized "commonalities between scholars" working on leprosy in fields not normally brought together

This was very exciting to me; it marks a new approach to Hansen’s disease studies across disciplines, informed by post-colonialism. Rather than focusing on the institutions themselves, or medical and governmental treatment of those with the disease, the papers were united

in their focus on the people who were diagnosed and living with the illness, and social responses to Hansen’s disease as human experience.

For example, Professor Aleksandra Pfau introduced remission letters from 15th century France, typically written by those seeking the king’s pardon and remission for a crime. While formulaic, some of these letters made mention of the illness and the authors’ experiences in the community and in hospitals, which Pfau used to introduce the complexities of community responses to Hansen’s disease and the fluidity of treatment and diagnosis.

This approach was echoed in the presentation by

Professor Keri Inglis, who read letters, memoirs and introduced oral histories to describe the ways in which people diagnosed with Hansen’s disease imagined their community and the landscape of their institution.

What emerged was a multifaceted examination of Hansen’s disease through history and around the world that emphasized the commonalities between scholars working on the illness in fields that are not usually brought together. Moreover, by breaking down academic barriers through a focus on the person affected by the disease, this phenomenal collection of presentations may prove to be an important step in shifting public attitudes and discourse that continue to evoke Hansen’s disease as a threat to the social order, despite the availability of a medical cure.

Kathryn M. Tanaka is a tenured lecturer at the Faculty of Historical and Cultural Studies, Otemae University, Japan. Her main area of study is Hansen’s disease literature, in particular the ways in which community is created in literature by people who have experienced the illness. She is currently completing her book, Through the Hospital Gates: Community in Japanese Hansen’s Disease Literature.

Profoundly Misunderstood

Tokyo Albinism Conference touches on some familiar themes for leprosy.



A first for Japan: an international conference on albinism

Albinism is a genetically inherited condition. Leprosy is an infectious, curable disease. But in terms of society's response, they share some unwanted similarities.

The recent Tokyo Albinism Conference highlighted the ways in which ignorance, superstition and mistaken beliefs about people perceived as different can have harmful—and, especially for persons with albinism—deadly consequences.

The conference was organized at the initiative of Nippon Foundation Chairman Yohei Sasakawa, who on his travels to Sub-Saharan Africa as WHO Goodwill Ambassador for Leprosy Elimination had become aware of the violence and discrimination that persons with albinism face. It drew panelists from Tanzania, Kenya, Malawi, Hong Kong, Canada, as well as host country Japan, among others.

Many with the condition live in fear of being assaulted or killed for their body parts.

Albinism prevents the body from producing melanin, the pigment that colors the skin, hair and eyes. Those born with the condition have reduced vision and are more susceptible to skin cancer—many people die before the age of 40 if they do not take proper precautions.

In North America and Europe, 1 in 17,000-20,000 people have albinism, but the prevalence rate is much higher in Sub-Saharan African countries such as Tanzania, where it is estimated at 1 in 1,400 people.

Problems persons with albinism encounter range from name-calling through discrimination in education and employment to violent physical attack. In Sub-Saharan Africa, because of superstitions that they have special powers, many with the condition live in fear of being assaulted or killed for their body parts, which are used by witchdoctors to make magic potions or amulets. Fueling the lucrative trade are politicians who consult witchdoctors because they want to stay in

power, and wealthy business people who want to be more successful.

According to the UN independent expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, there have been some 700 documented attacks on persons with albinism in 28 countries since 2006, involving murder, mutilation and sexual violence—and those are just reported cases.

A survivor of one such attack spoke at the conference. Ten years

ago, Mariamu Staford was set upon in the night by four men, including a neighbor. Her arms were hacked off in front of her child, and she lost the unborn baby she was carrying.

A journalist who went undercover to investigate the lucrative trade in body parts for the BBC found her report displeased the authorities, for whom the image of the country was more important than the human rights of persons with albinism. "I was told I had tarnished the reputation of Tanzania," said Vicky Ntetema.

WRONG THINKING

As with efforts to reduce the stigma and prejudice associated with leprosy, education and advocacy are crucial to changing mindsets.

"Wrong thinking exists in every culture," said Peter Ash, who founded the NGO Under the Same Sun for persons with albinism. "There is misinformation around this condition even in countries with high levels of medical care."

Governments need to be sensitized—"some government departments have no understanding of the issue," the conference was told—and there needs to be political will to protect persons with albinism.

There needs to be engagement with media, with religious leaders and with tribal chiefs to increase acceptance of persons with albinism.

Albinism needs to be fully recognized as part of the disability sector, with access to the considerable resources that exist there. The role of the judiciary is important to upholding the law and in prosecuting crimes against persons with albinism.

In particular, there is a need for more positive role models for persons with albinism—public figures such as the judge and the parliamentarian among the panelists—who can inspire through their words, deeds and successes, and help change society's perceptions.

"Nobody will accept us until we accept ourselves," said Connie Chiu, a Hong Kong-born person with albinism who has made a name for herself as an international fashion model and jazz singer. "I have albinism. So what? Those with the problem are society." ■



Model and jazz singer Connie Chiu: "I have albinism. So what?"

A Coordinated Approach to Leprosy

On his latest visit to Indonesia, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa is encouraged to see the government take a multi-sectoral approach to tackling the medical and social dimensions of the disease.



With participants in the meeting at the Coordinating Ministry for Human Development and Culture in Jakarta on Oct. 2.

INDONESIA (October 1-6)

In October I returned to Indonesia, visiting Jakarta, the capital, and Maluku Province in the eastern part of the country. Just days before my arrival, Central Sulawesi had been struck by an earthquake and tsunami, causing tremendous damage and casualties. I had visited Central Sulawesi in March and my heart went out to all affected.

The purpose of my latest mission was to discuss with the central and provincial governments, as well as with PerMaTa, an organization of persons affected by leprosy, how to further reduce the number of cases of leprosy in Indonesia and eliminate leprosy-related stigma and discrimination. I had also arranged to continue my advocacy work through local media.

My first appointment was with the Coordinating Ministry for Human Development and Culture in Jakarta on October 2. The ministry is one of four coordinating ministries that are a distinctive feature of Indonesia's system of government.

The Coordinating Ministry for Human Development and Culture has a wide brief, covering health, education, religious affairs, female empowerment and child protection, as well as villages, disadvantaged regions and transmigration, among others. As the name suggests, its role is to coordinate and synchronize policy formation and governance in these different areas. The coordinating ministry has overall responsibility for anti-leprosy activities in the country and had organized its first awareness meeting on leprosy to coincide with my visit.

Dr. Sigit Priohutomo, deputy minister for health improvement, is very knowledgeable about the disease, having worked at a leprosy clinic for five years and engaged in case-finding activities. "Leprosy is not

only a medical issue," he said. "It is also accompanied by discrimination and stigma. To tackle it we need the cooperation of not only the health ministry but of other ministries too. That's why I have brought together the relevant people for this meeting."

As Goodwill Ambassador, I have traveled to many countries over the years promoting leprosy elimination activities, but I have not participated in many meetings about leprosy involving high-level bureaucrats drawn from different ministries and agencies. I felt it was a very encouraging sign as a multi-sectoral approach is required to deal with all the issues associated with leprosy and its consequences.

Some 30 people took part, including bureaucrats from Dr. Sigit's ministry, and from ministries and agencies under its jurisdiction; bureaucrats from ministries such as home affairs, industry and communication that are under the wing of other coordinating ministries; and the chairman and vice-chairman of PerMaTa.

One of the issues I have found in leprosy-endemic countries is that while there is recognition of the need to find as many new cases as possible, among those in charge there is sometimes the fear that they will be held responsible for an increase in case numbers. Meanwhile, there remains a deep-rooted fear and shame associated with a diagnosis of leprosy that can prevent those who need treatment from seeking it. Taken together, these are some of the reasons why leprosy programs do not always function as well as they should.

That's why I was delighted to hear Dr. Sigit say: "Finding new cases is not something to be ashamed of but something to be proud of; let us consider it a privilege to find new cases."



Dr. Sigit Priohutomo, deputy minister for health improvement

He also had words of praise for PerMaTa's Paulus Manek and Al Kadri, who had talked about their personal experience of the disease, their battles with stigma and their current activities to help other persons affected by leprosy. "Your words have many implications for us. Self-stigma is a difficult issue, but you have turned it into something positive."

That evening, I was interviewed by the *Jakarta Post*. The English-language newspaper's youthful managing editor is Mr. Ary Hermawan. He told me that his mother is a person affected by leprosy and that he is committed to promoting understanding and awareness through the media. As one who has always viewed the media as a vitally important partner in the fight against leprosy, I was very encouraged to hear this.

On October 3, I flew 2,500 kilometers east of Jakarta to Ambon, the capital of Maluku Province. Of Indonesia's 34 provinces, Maluku has the fourth highest number of cases annually, while its capital, Ambon, has a prevalence rate of the disease of 2.49 per 10,000 population. This is one of the provinces where efforts against the disease will need to be ramped up if Indonesia is to achieve its goal of eliminating leprosy as a public health problem in all 34 provinces by 2019 and all districts by 2024.

During my stay, I attended a stakeholders' meeting at the offices of the provincial government attended by Governor Said Assagaff and representatives from various departments and agencies. One of the challenges Maluku faces is geographic: the province is made up of some 1,500 islands and is 70% jungle, making access to patients difficult. In addition, stigma and discrimination remain deep-rooted, so patients and their families make efforts to conceal the disease, resulting in delayed diagnosis and treatment.

As part of my effort to dispel myths about the disease, I appeared on Televisi Republik Indonesia (TVRI) later in the day to talk about leprosy. I put great faith in reaching people through local media and take every opportunity to meet with journalists

and take part in television and radio programs.

Appearing with me were PerMaTa's chairman, Paulus Manek, and Dr. Ritha Tahitu, head of disease control at Maluku's provincial health department. We stressed the importance of early diagnosis and treatment; said that leprosy was neither a curse nor a punishment nor a hereditary disease; assured that it was curable and not something to be fearful of; and urged family members to check each other for skin patches that are symptoms of the disease.

"Self stigma is a difficult issue, but you have turned it into something positive."

The next day I continued my media work, appearing on a radio phone-in program on RRI (Radio Republik Indonesia). It is always of great interest to me to hear the kinds of questions people ask about leprosy and remind myself that we can never do too much to inform the public about the disease.

Although only a short program, there was enough time for several listeners' questions, including "What country did leprosy originate in?" "What should I do if I'm diagnosed with leprosy?" and, doubtless prompted by my country of origin, "Is Japan taking the lead in leprosy elimination activities?"

I had been scheduled to attend another stakeholders' meeting in the company of Ambon's mayor, but unfortunately he had been called away on urgent business. The meeting went ahead as planned, however, and it was another opportunity to stress that leprosy is not solely the responsibility of the health department but requires the involvement of other sectors of society, especially when it comes to correcting misperceptions of the disease, addressing discrimination and creating conditions where someone can seek treatment without fear.

Among those taking part were a number of persons affected by leprosy. They included a pastor diagnosed with leprosy in 2017 who had been



Appearing on TVRI (Televisi Republik Indonesia) to talk about leprosy.



(Right) In the studios of RRI (Radio Republik Indonesia); (far right) Paulus Manek (back to camera) discusses plans for a branch of PerMaTa in Ambon, Maluku Province.



discriminated against by his family and neighbors. “A pastor’s job is to help families in need, but when I became ill with leprosy I was shunned by society,” he said. But he made a point thanking an Ambon health worker who had come to his rescue and showed him unlimited kindness.

“If there is somebody with leprosy near you, please show them compassion,” he said, adding that only those who have experienced the disease for themselves can truly understand the pain of stigma. “Mr. Sasakawa, don’t forget people like me.”

Toward the end of the meeting, PerMaTa’s Paulus Manek rose and introduced himself. He asked persons affected by leprosy in the room to raise their hands and explained that PerMaTa was planning to open a branch in Ambon. “Are you all in favor?” he

wanted to know.

He then went on to explain PerMaTa’s mission and role in building a society free from stigma and discrimination, the challenges involved and the commitment required. Perhaps it was Paulus’s straightforward approach and enthusiastic manner, but when he asked them a second time about whether or not there should be a branch of PerMaTa in Ambon, their answer was a resounding yes. Paulus then declared: “I now formally declare the opening of the Ambon branch.”

I was very happy to present at this moment. Changing society involves grassroots efforts as well as initiatives at the upper echelons of government. On my latest visit to Indonesia, I had witnessed examples of both. ■

MAKING A DIFFERENCE

In the various discussions I attended together with Paulus Manek, I had the chance to hear him explain to government officials, TV viewers, and persons affected by leprosy what motivates him in his work as chairman of PerMaTa, Indonesia’s organization of persons affected by leprosy founded in 2007.

Paulus, who was born into a poor family, contracted leprosy as a boy, but neither he nor those around him knew the significance of the white patches that had appeared on his skin. His mother took him to see a doctor, who prescribed some medicine that he took for a year and a half. It wasn’t cheap and it didn’t work. Only later did a local priest advise him to go to a health clinic where he could get proper treatment with MDT, and for free.

At home, his father and siblings distanced themselves from him because they didn’t know how the disease was transmitted or how it was cured. His symptoms worsened and his fingers began to bend out of shape. He thought of running away and even giving up on life altogether. But when treatment with MDT began to take effect, he resumed his education. He was the only person in his family to graduate from high school and

went on to study at university.

It was when he encountered PerMaTa that he found his motivation in life.

“Through PerMaTa, I want to make sure that people don’t have to

go through the same things that I did. I’ve experienced discrimination and isolation. Now I am able to help other persons affected by leprosy and give them opportunities to lead a normal life.

“What we need is a change in society’s mindset. I have some small residual disability as a result of leprosy, but it’s not a problem. I could have had my fingers straightened, but I keep them this way as evidence that I once had leprosy. The problem is social stigma, and the fact that people think leprosy is a curse, or that it’s very contagious.

“As persons affected by leprosy, we know all about the disease and understand the feelings of leprosy patients. We hope the health authorities appreciate that and allow us to play a role. There are cases



Paulus Manek is readied for a TV appearance (left) and hands information about PerMaTa to a prospective member in Ambon, Maluku Province (right).

when patients stop taking their MDT for whatever reason, but by becoming involved we can help them resume their treatment.”

I was especially impressed as I listened to Paulus pitch the idea of forming a new branch of PerMaTa in Ambon to potential members.

“You won’t get a salary from this work. You won’t get rich. But what you will be doing is helping people.”

I heard Paulus say more than once that he does not want others to have to experience the hardships he endured. But at the same time, he also said he is grateful for the opportunities leprosy has given him.

As I watched him talk passionately about having a positive impact on the lives of others, I understood well what he meant.

Global Leprosy Update 2017

10-year trend characterized by slow but steady decline.

In 2017, a total of 210,671 new leprosy cases were detected and reported to the WHO by 150 countries, as detailed in the annual global leprosy update published in the *Weekly epidemiological record*.^{*} This represents a decrease of around 7,000 cases compared to 2016. At the end of the reporting year, 192,713 patients globally were recorded as being “on treatment.”

As in previous years, the WHO’s Southeast Asia Region accounted for the bulk of the global leprosy burden, with two countries, India and Indonesia, contributing 67.4% of new leprosy cases globally and 92.6% regionally. Brazil contributed 92.3% of new leprosy cases in the Americas Region. Together these three countries—India, Brazil

and Indonesia—accounted for 80.2% of the new caseload globally in 2017.

Twenty-two countries are designated as global priorities. Except for South Sudan, which did not report data, these countries reported 95% of all new cases. While there was an overall reduction in the number of new cases detected in global priority countries compared to 2016, increases in the number of new cases were observed in seven countries: Bangladesh, Brazil, Comoros, Mozambique, Nepal, the Philippines and Sri Lanka.

The 10-year trend between 2008 and 2017 is characterized by a slow but steady decrease in the number of new cases detected globally, down from 249,007 in 2008.

^{*}Since the global leprosy update was published on 31 August, the WHO has now received reports from 159 countries and territories—the highest number ever—and adjusted the total of new cases detected in 2017 to 210,942.

WORKING GROUP

The Global Partnership for Zero Leprosy is launching an Operational Excellence Working Group. Anyone working in leprosy or affected by leprosy is invited to apply to join the working group, which is to foster the development, use,

scale-up, monitoring and evaluation of best practices and promising innovations in national leprosy programs. Applications are accepted through 31 December 2018.

For more information, visit zeroleprosy.org ■

FROM THE EDITOR

THE BIGGER PICTURE

Ikponwosa Ero, the UN independent expert on the enjoyment of human rights by persons with albinism, first made an appearance in these pages two years ago in our coverage of the 2016 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy launched from Tokyo. She had been one of six panelists in a session titled “Health and Human Rights—Combating Discrimination” discussing some of the challenges facing those with leprosy and other diseases, disabling conditions and health impairments.

She was back in Japan last month for the Tokyo Albinism Conference (see page 4), organized by Nippon Foundation Chairman Yohei Sasakawa, who in his capacity as WHO Goodwill Ambassador for Leprosy Elimination makes countering stigma and prejudice a core feature of his work. As Ms. Ikponwosa ran through the spectrum of discrimination that persons with albinism face, it was a timely reminder that beyond the need to address stigmas specific to albinism—or leprosy or any other disability—fostering an inclusive society in which

everyone is treated with dignity and respect is key.

Two women with disabilities—Nidhi Goyal, an activist and comedian from India, and Mayaan Ziv, a fashion photographer and entrepreneur from Canada—addressed this issue recently on the BBC World Service radio series “The Conversation.” Both agreed that social attitudes were the No. 1 thing that needed changing, since social attitudes, or environments or “the way we design our worlds” are the actual disabling factor that limits a persons with disability from living they way they want to.

“We need to be comfortable with asserting a level of standards, of, quite frankly, human rights, that other people take for granted,” said Ziv. “If you live with a disability, then speaking up and having your voice heard in any opportunity is really important.”

For the non-disabled, Goyal had this advice about giving those with disabilities “a seat at the table.” She made the point that it’s also about recognizing that “you’re not giving anyone the space, you’re not creating a space for anyone, because the space belongs to all of us.” It is a message worth repeating.

FOR THE ELIMINATION OF LEPROSY

Publisher

Yohei Sasakawa

Editor

Jonathan Lloyd-Owen

Layout

Ryo Mogi

Photographer

Natsuko Tominaga

Editorial Office

5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku,
Tokyo 107-8404
Tel: +81-3-6229-5377
Fax: +81-3-6229-5388
smhf@tnfb.jp

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Sasakawa Memorial Health Foundation,
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www.nippon-foundation.or.jp/en/
www.smhf.or.jp/e/