

# FOR THE Elimination OF Leprosy

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



Residents of Tesfa Hiwot, a community of people affected by leprosy in Ethiopia, enjoy a light moment during the Goodwill Ambassador's visit in April.

MESSAGE

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## No Shame in Increased Case Numbers

People may be surprised to hear me say that I would like to see an increase in case numbers, but I have my reasons.

For many years we have focused on lowering numbers, using the WHO's target of reducing prevalence of leprosy to less than 1 case per 10,000 people in order to eliminate the disease as a public health problem. I remain convinced that setting this numerical target was correct. Today, the fact that only Brazil and a few small island nations have yet to achieve it is a mark of its effectiveness. As I have said before, however, 'elimination' is only a milestone en route to the ultimate goal of eradicating the disease altogether.

But in many countries that have achieved elimination, there has not been a significant reduction in new case numbers in the years since. One reason, I feel, is that by focusing on reducing numbers we have, without realizing it, come to suffer from a kind of trauma. With attention focused on lowering case numbers, no one has been willing to focus on activities that could result in an increase, fearing the criticism that might come their

way. But there is nothing to be ashamed of in seeing patient numbers increase.

When I visited the DR Congo recently, I learned that the health ministry's action plan for leprosy is to increase the number of newly-detected cases by 50%. To achieve this, they expressed a determination to actively seek out new cases. An action plan such as this will invariably lead to a temporary rise in new cases, but it will also increase early detection and result in a reduction in new case numbers in the long run.

I'll say it again, but an increase in patient numbers is not something to be ashamed of; it should be commended as a sign of an active program. There are still people suffering from leprosy in places we don't know about; there are still leprosy hot spots. Let us go all out and find these new cases. That was the spirit behind the 2013 Bangkok Declaration; that was the reason why the Nippon Foundation committed an additional US\$20 million to anti-leprosy activities.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Ending Discrimination: Next Steps

Symposium series concludes with recommendations of International Working Group.

The fifth and final symposium in a series on leprosy and human rights organized by the Nippon Foundation was held in Geneva on June 18. Initiated as a follow-up to the 2010 U.N. General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members, the aim of the series was to disseminate the principles and guidelines accompanying the resolution and to ensure their effective implementation.

An International Working Group (IWG) composed of human rights experts, legal scholars and people affected by leprosy was formed after the first symposium in Rio de Janeiro in 2012 and met four times in order to formulate plans of action and a mechanism to monitor actions taken by states and other actors. Its report on “How to Follow Up the U.N. Principles and Guidelines” was presented at the Geneva symposium.

Co-hosted by the Graduate Institute of International and Development Studies, the day-long event featured a full program of speakers and panelists. The keynote address was delivered by WHO Goodwill Ambassador Yohei Sasakawa, preceded by video messages from U.N. Secretary-General Ban Ki Moon and WHO Director General Margaret Chan.

Dr. P.V.R. Rao of the WHO’s Global Leprosy Program provided delegates with an overview of the current status of leprosy in the world, while two separate panel discussions featuring people affected by leprosy from Indonesia, Morocco, Colombia, China, India, Ghana, Brazil and the United States gave their personal insights on the challenges of living with discrimination, actions being taken to overcome stigma and their hopes for the principles and guidelines.

Also presenting their views on how their organizations can help to end the discrimination associated with leprosy were representatives from the International Bar Association, the Jordan National Center for Human Rights, U.N. Human

Rights Council Advisory Committee, International Federation of Anti-Leprosy Associations, World Medical Association, International Council of Nurses and Sasakawa Memorial Health Foundation.



Delegates, speakers and IWG members in Geneva: previous symposiums were held in Rio de Janeiro, New Delhi, Addis Ababa and Rabat.

## MONITORING MECHANISM

Presenting the IWG’s report was Professor Barbara Frey, director of the Human Rights Program of the University of Minnesota. The group’s key recommendation was the establishment of an international mechanism to monitor the conduct of states and other actors in order to implement the principles and guidelines effectively. In addition, the IWG drafted a framework for model national plans of action and compiled a questionnaire to assist in investigating the actual status of implementation.

“We know where we want to go, which is the full implementation of the principles and guidelines. This mechanism is how to get there,” Professor Frey said.

**“We know where we want to go, which is the full implementation of the principles and guidelines.”**

## QUOTE

“Your focus on the people themselves who have leprosy is so important. HIV/AIDS showed us that people living with AIDS made the difference. They exerted the political pressure. They moved into society, saying, ‘We belong here; this is where we want to be.’”

— Professor Ilona Kickbusch, Director, Global Health Programme, Graduate Institute, addressing the symposium on leprosy and human rights



United we stand: (L to R) Naima Azzouzi, Jose Ramirez, Jr. and Jaime Garcia at the Geneva symposium on June 18

Specifically, the IWG suggested that the U.N. Human Rights Council entrust its Advisory Committee, which was responsible for drawing up the principles and guidelines in the first place, to study and recommend an appropriate follow-up mechanism.

A Japanese government resolution along these lines was submitted at the 29th session of the Human Rights Council meeting in Geneva from June 15. It requested the Advisory Committee to undertake a study reviewing the implementation of the principles and guidelines and submit a report by 2017 with suggestions for their wider dissemination and more effective implementation. Co-sponsored by 94 countries, it was adopted unanimously. ■



# ‘People Won’t Go Near Us’

Panelists from Brazil to Morocco share their thoughts at the Geneva symposium.

**Naima Azzouzi**  
(Association Accompanying People Affected by Leprosy, Morocco)



People who live with leprosy are still suffering from discrimination in my country. We find it difficult to find work, and people won’t go near us or touch us. Additionally, doctors are often scared of

working with us. We have created a small association for people affected by leprosy and their families, but unfortunately we are not able to operate properly because we receive no help whatsoever. People are scared of working with our association.

**Paulus Manek**  
(PerMaTa, Indonesia)



People affected by leprosy do not want to be pitied; we want to be accepted and treated as human beings. There are still many people with leprosy hidden in remote areas of Indonesia. The more awareness there is of

leprosy, the higher the chances of finding new cases. The government is doing a lot, but it can’t do everything. We can help.

**Wu Yao Qiang**  
(HANDA, China)



The government pays more attention to discrimination in economically well-developed areas. But in some very rural leprosy villages, people are still living in very difficult circumstances. The government just provides

some food and a little money, but it doesn’t take any actions to eliminate discrimination.

**Jaime Garcia**  
(Coroshansen, Colombia)

A major contributor to the spreading of leprosy stigma was the government, which brought people from all over the country to live in small



**Kofi Nyarko**  
(IDEA Ghana)



IDEA Ghana has a grass-roots approach to ensure human rights. We have seen through our experience that the people themselves are the best participants in this process. This has always been the strength of IDEA and the network it develops. In Ghana, human rights have been achieved through an individualized, personalized approach. The government has not been involved.

**Valdenora Rodriguez**  
(MORHAN, Brazil)



We have been continually discriminated against because of the word “lepra.” It represents fear, a threat. My mother was a teacher and was left with no students because I, her daughter, had leprosy. Our mission to Pope Francis was to

extinguish this word, to stop its use so that we can rescue our dignity and recover our identity that was once stripped from us.\*

**Vagavathali Narsappa**  
(APAL, India)



Children should know from an early age about this disease. They should understand what leprosy is. I feel strongly that if leprosy is taught to children as a subject at school, this will influence their behavior and help to reduce stigma. ■

## QUOTE

“Some good things are happening in India. I suggest that our experience should stand as a model for other countries to learn from. For this, we should have a lot of communication between the people. That should be the future.”

— Dr. P.K. Gopal, IDEA India (Moderator)

“In the next five years, the 60 of us who are still alive who were institutionalized at the National Leprosarium in Carville, Louisiana, may be too weak to carry on the role of advocates. I believe that the new generation of our children, their cousins, and others of their age will carry on.”

— Jose Ramirez, Jr., IDEA USA (Moderator)

## FOOTNOTE

\* See page 8, “An Audience with the Pope”

# Leprosy and the Law

The position in international law could not be clearer: no discrimination.

Modern international law was inspired by the Universal Declaration of Human Rights. It is very clear that the discrimination faced by people affected by leprosy is a direct violation of the rights and dignities offered to all people under that declaration.

The detail of international law is in U.N. treaties and conventions and they become binding on a country if it signs them. From that moment, a country is obligated; it must alter its own laws to comply with everything it has signed up to. Over the years, more and more rights have been written into treaties and guaranteed to citizens in this way.

As examples, we have conventions on the rights of the child, against torture and, particularly relevant to leprosy, on the rights of persons with disabilities. This was agreed in 2006 and declares that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person. It says states must protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

If that wasn't clear enough, the U.N. took a further step in 2010 when the General Assembly adopted its resolution on elimination of discrimination against persons affected by leprosy and their family members. That title speaks very plainly. The position in international law could not be clearer: no discrimination.

More importantly, the resolution has set a new global agenda and is continuing to set it, based on the work of the advisory group\* and the proposal for an official way of monitoring the progress of countries toward completing the promises made in the principles and guidelines that accompany the 2010 resolution. That soft law is on its journey to becoming hard law.

What international law is doing is setting an example, setting a pace. It is putting more pressure on countries that do not live up to the standards set in that agenda. To keep encouraging the international agenda is a fundamental part of what we can do to make this better future.

## NATIONAL LAW "MUDDLED"

Sadly, in national law, the position in some countries is muddled and not so clear as we would like. There are still countries which have old laws that have never been repealed and that deliberately discriminate against those affected by leprosy. Such laws can be challenged these days, because they contradict international law. They can also be challenged because they contradict rights guaranteed to citizens by their country's constitution.

Most countries now have constitutions that

are fairly new or recently revised to draw on the enlightened language of international law. Many countries have established constitutional courts specifically to hear cases that make challenges to contradictory old laws.

The IBA will continue to urge and encourage lawyers and their national bar associations to work with leprosy-related NGOs to bring cases to court. As well as challenging old laws that are wrong, we want to see them removed and replaced by laws that guarantee all the rights guaranteed by international law.

## INDIA REPORT 'A MODEL'

I must commend the Law Commission of India on its recent report.\*\* India carries a special responsibility because it is the country with the most new cases of leprosy and the most laws discriminating against those with the disease.

The Law Commission rightly observes that the laws in India on this issue are a matter of shame. Its report is a model in setting out how to change the law, not merely to remove the old discrimination but to compel the state to provide those affected by leprosy with the social, economic and practical support which they need to help overcome the difficulties they face.

**Some countries still have discriminatory old laws that have never been repealed.**

Many other countries could learn much and achieve much by following the lead given by this remarkable report. I believe it should be circulated widely. It has been so clearly inspired by the 2010 U.N. resolution and accompanying principles and guidelines. It shows the road by which international law can travel to become new and better law at national level, although we still have much campaigning to do to make that happen in India.

We should continue to use these two documents, the principles and guidelines, and the India Law Commission report, to encourage lawyers and lawmakers everywhere to work until such new laws are introduced in all the countries where leprosy still diminishes lives in so unjust a way. The IBA will carry on working with the international community to keep heightening its awareness of this ongoing injustice, and to keep international law extending and deepening its focus and agenda-setting on this issue of leprosy and to treat those things with proper and urgent priority. ■

## PROFILE:

**Tim Hughes**



Tim Hughes is Deputy Executive Director of the International Bar Association (IBA), the global body of the legal profession. This is an edited version of his presentation at the International Symposium on Leprosy and Human Rights in Geneva on June 18.



The IBA and 46 member associations endorsed the 2013 Global Appeal to end stigma and discrimination against people affected by leprosy.

## FOOTNOTES

\* The International Working Group (see page 2)

\*\*Report No.256 on "Eliminating Discrimination against Persons Affected by Leprosy" (April 2015)

# Going the ‘Last Mile’

Dr. Ann Aerts outlines Novartis Foundation’s evolving strategy against leprosy.

## PROFILE: Dr. Ann Aerts



Dr. Ann Aerts is Head of Novartis Foundation. She assumed her post in 2013. Since 2000, Novartis has provided free multidrug therapy (MDT) to leprosy patients worldwide through the WHO and has guaranteed its drug donation through 2020.

### What drives Novartis’s commitment to tackling leprosy?

We have a legacy in leprosy, since two of the three drugs of MDT came out of the labs at Ciba-Geigy and are still working well. Our aim at the foundation is to have a transformational impact on the health of the poorest populations and the fight against leprosy is very important to us and the company.

### Where does leprosy fit into the foundation’s overall activities?

We have two main axes to our programs. One is disease elimination, and leprosy is the main part of that; the other is health impact focused on improving access to healthcare and exploring innovative healthcare solutions.

### How has the foundation’s strategy for leprosy changed since you took over?

The new strategy focuses on interrupting leprosy transmission through early diagnosis and prompt treatment, tracing and prophylactic treatment of contacts of newly diagnosed patients, strict surveillance and response, and development of diagnostic tools.

### Is the goal of zero transmission realistic?

For now it is probably utopian, but I believe it is realistic. It needs to be accompanied by socio-economic development, which would have a huge effect on communities with a lot of cases of leprosy.

### How did your new strategy emerge?

In 2013 we hosted an experts’ meeting, bringing together leading experts in leprosy and other disease control programs. We launched the new leprosy strategy based on the consensus reached by the group. One of the key conclusions from the meeting is that we really have to apply contact tracing, as is done in TB in low-endemic countries, and offer preventive treatment. Based on that, we have embarked on a program with pilot areas in six countries where we will consider every new leprosy patient and do contact tracing around him/her and offer a preventive treatment to all the contacts. Trials have shown that preventive treatment has proven to be efficient in reducing the risk of developing leprosy in the following years by half. We aim to gather enough data to demonstrate whether this approach will have an impact on the incidence of leprosy.

### What are some of the other elements?

We are also doing research for biomarkers to develop a diagnostic test because we are convinced that if we want to eliminate leprosy we will need an objective measurement of who is infected and who is at risk of

developing the disease. Another part of our work is supporting three universities to develop mathematical modeling to better guide the efforts to leprosy elimination. The models should help us understand the potential impact and cost-effectiveness of new interventions compared to intensified routine programs. We are also looking at innovative ways to accelerate the clinical diagnosis, such as using mobile phones. We want to make it easier for even unskilled health workers in remote areas to consult someone who has the expertise to confirm a diagnosis.

### You have made no mention of a vaccine.

There is important work being done by other players; if a new vaccine were to be found, it would have to prove to provide better protection than BCG.

“You really need to invest in the end, because the end is the most difficult part.”

### Why did you feel the need to seek advice from other disciplines?

I transitioned from Novartis to the Novartis Foundation and seeking multi-disciplinary and multi-sectoral input is the company’s approach. We are constantly challenging ourselves and gaining as much expert input as we can from outside, and I felt we needed that in leprosy. The challenge in leprosy is that there is limited evidence on strategies for going the ‘last mile’. I was constantly challenging the experts: why do you do this and not what is documented as evidence? That’s where I thought there was definitely a role for the Novartis Foundation, as we are coming from a science-based, evidence-driven organization.

### What else is needed to defeat a disease like leprosy?

You need to have partnerships, you need the involvement of the local community and you really need to invest in the end, because the end is the most difficult part. I heard a Japanese saying that “the last mile is only half way,” and it’s absolutely correct. Think of the investment made in India to eradicate polio: going from village to village, from house to house. We may be obliged to do something similar for leprosy, and for that you need huge political commitment. You also need people like Mr. Sasakawa to continue to advocate for leprosy. If this kind of voice can ensure that governments do not forget leprosy, then that is definitely an advantage where we can all go the last mile. ■



# Visits to Africa, Europe and the U.S.

Field visits to Ethiopia and DR Congo, meetings with ministers at the World Health Assembly in Geneva and awareness-raising in New York.

## ETHIOPIA (APRIL 2-5)



Residents of Tesfa Hiwot, Ethiopia

This was my first visit since the regional symposium on leprosy and human rights held in Addis Ababa in September 2013. Ethiopia reported 4,374 new cases of leprosy that year, a figure more or less unchanged for the past decade. Of this total, children accounted for 13% and cases with Grade 2 (visible) disability for just over 10% — levels that indicate ongoing transmission and delays in diagnosis.

Ethiopia's health ministry now has a plan to strengthen case detection, taking advantage of the special fund set up after the 2013 International Leprosy Summit in Bangkok. It has submitted a three-year project proposal that focuses on capacity building at the primary health care level, supporting the national leprosy program and boosting advocacy, communication and social mobilization.

Health Minister Dr. Kesete Admasu told me that the ministry had recently carried out mapping of high-endemic areas to find out where leprosy is concentrated, and would be focusing on these areas from now on. He also revealed that 5,000 nurses were being given an opportunity to learn about leprosy and would participate in elimination activities. In addition, he said the ministry would be enhancing its cooperation with the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) in aiming to reduce new cases to zero.

Founded in 1996, ENAPAL has gone from strength to strength. It now has a total of 63 branches in eight out of Ethiopia's nine states. There are few other organizations of people affected by leprosy on this scale anywhere else in the world.

I met with ENAPAL leaders during my stay and visited two communities of people affected by leprosy to inspect a vegetable farm and a poultry farm begun with microloans provided by Sasakawa

Memorial Health Foundation. Ethiopia faces many challenges in detecting and treating new cases and reintegrating those affected by the disease, but I believe it is moving in the right direction.

## DEMOCRATIC REPUBLIC OF CONGO (APRIL 5-10)

The DR Congo eliminated leprosy as a public health problem in 2008 but still has hot spots of the disease in the country. The 3,744 new cases it recorded in 2013 was the second highest number in Africa after Ethiopia and the fifth highest in the world.

Dr. Mputu, the long-serving national program manager, told me there were eight provinces where the prevalence rate is more than 5 cases per 10,000 population. He said the health ministry is targeting these eight provinces for specially strengthened elimination activities and they will be making an all-out effort to find new cases.

The country has submitted a project proposal to the Bangkok special fund that targets increasing new-case detection by 50% in order to help break transmission of the disease. I told Dr. Mputu I thought this was a bold and necessary initiative.

Accompanied by Health Minister Dr. Felix Kabange Numbi Mukwampa, I called on National Assembly Speaker Dr. Aubin Minaku. Engaging with political leaders is important for raising awareness of leprosy. I asked the speaker to use his position to encourage parliamentarians to tell their constituents that leprosy is curable, treatment is free, and that discrimination has no place.

The next day, together with Dr. Kabange and Dr. Mputu, I flew to Equateur Province, one of the eight provinces where prevalence of the disease remains high. From the provincial capital Mbandaka we drove into jungle to visit communities that see cases of leprosy among the pygmy population.

Our journey was hampered by torrential rain and several times we had to wait for repairs to bridges



Heavy going in DR Congo's Equateur Province



The Goodwill Ambassador in action in Tesfa Hiwot

along our route. In the end, we were only able to reach the first of our two intended destinations, where I visited a health center and met two men from the Batwa tribe who were being treated for leprosy. The trip was a vivid illustration to me of the realities involved in delivering health care services to the remoter parts of the country.

On my final day in the country I met Dr. Victor Makwenge Kaput, the former health minister and now a National Assembly member. He said that although leprosy still stigmatizes, the public is coming to know that treatment is free and that it is possible for people who are diagnosed with leprosy to continue to live with their families. It was an encouraging note on which to end my trip.

**SWITZERLAND (MAY19-22)**

While in Geneva for the World Health Assembly to present this year's Sasakawa Health Prize, awarded

to Poland's Childbirth with Dignity Foundation, I took the opportunity to meet with health ministers or their representatives from 11 countries: Brazil, China, Democratic Republic of Congo, India, Indonesia, Madagascar, Mozambique, Myanmar, South Sudan, Sudan and Tanzania.

In addition to discussing the leprosy situation with them, I wanted to encourage those that had not taken advantage of the Bangkok special fund to submit project proposals to strengthen case-finding activities. I also asked for their governments' support for a follow-up resolution on elimination of discrimination against persons affected by leprosy that the Japanese government was planning to introduce at the 29th session of the Human Rights Council between June 15 and July 3. On both the medical and social fronts, we need to continue to devote ourselves to doing all we can to tackle the disease and the discrimination it causes. ■

**LEPROSY AND THE DISABILITY MOVEMENT**



On June 9 I was at the United Nations in New York to give the keynote address at a side event of the annual conference of states parties to the Convention on the Rights of Persons with Disabilities. "Voices of People Affected by Leprosy" featured leprosy for the first time in the history of the

conference and I am very grateful to Mr. Javed Abidi, the chairperson of Disabled People's International, for helping to make this happen.

He told the event that more had to be done to bridge the gap between communities of people affected by leprosy and those otherwise disabled, saying that among disabled people there should not be any discrimination and that "these two groups have to be brought together so we can inspire each other and give each other confidence."

Giving the viewpoint of people affected by leprosy were Mr. Jose Ramirez, Jr. of IDEA USA and Dr. P.K. Gopal. of IDEA India. Dr. Gopal (in

photo) said that among the immediate needs of people affected by leprosy in his country, educational support for their families was very important for improving their children's quality of life. "Not only leprosy-affected people, but children who do not have leprosy, also suffer from stigma and discrimination."

I told the audience of around 70 people that I hoped this event would be the start of fresh opportunities for cooperation among all persons with disabilities and that it would create new possibilities to shorten the long road ahead to creating a truly inclusive society. As Mr. Ramirez rightly said in his presentation, "We made history today."



# An Audience with the Pope

People affected by leprosy from Brazil meet Pope Francis, discuss terminology.



A delegation from Brazil met with Pope Francis in St. Peter's Square, Vatican City, on June 17. The group included Valdenora Rodriguez and Faustino Pinto, both persons affected by leprosy, as well as Artur Custodio, the national coordinator for the Movement for the Reintegration of Person's Affected by Hansen's Disease (MORHAN), and Thiago Flores, MORHAN's coordinator for Minas Gerais state in southeast Brazil, who was separated at birth from his parents because they had leprosy.

The meeting, which was some two years in the making, was arranged through Bishop Diogo Reesink, O.F.M., a Dutch-born bishop emeritus

of the diocese of Teofilio Otoni in Minas Gerais.

Rodriguez (in photo) was the first to greet the Pope. She gave a brief account of her life before asking him not to refer to the disease as "leprosy" but as "Hansen's disease." Brazil officially adopted the term "hanseníase" in 1976 in place of "lepra" because of the latter's associations with marginalization, discrimination and prejudice.

Flores told Pope Francis that in order to end the discrimination against leprosy in Brazil, the support of the Catholic Church was essential. "Your Holiness's words are

influential. We call upon you to ask the Church not to use the word 'leprosy'."

He also requested that the Pope see a former colony where people were isolated from society on his next visit to Brazil.

Among the group was Tatsuya Tanami, executive director of the Nippon Foundation, who presented Pope Francis with a letter from Nippon Foundation Chairman and Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa. In the letter, Sasakawa proposed hosting a joint meeting with the Vatican for discussing strategies to eliminate the stigma associated with leprosy from the world. ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### A NEW RESOLUTION

The news that the U.N. Human Rights Council has unanimously adopted a resolution by the Japanese government asking the council's Advisory Committee to conduct further research on leprosy is a welcome one. It was a Japanese government resolution that set in motion the process that led to the 2010 U.N. General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members.

The much-lauded principles and guidelines that accompanied the resolution are a road map to restoring the human rights of every person affected by leprosy, yet they have no binding authority. For that reason, the Nippon Foundation organized a series of symposiums

on leprosy and human rights that led to the formation of an International Working Group to look at ways of encouraging states and other actors to implement them. The group has now produced its report containing its suggestions. It is to be hoped that the Advisory Committee will have taken due note when it reports back to the Human Rights Council in 2017.

The road to achieving full implementation of the principles and guidelines may seem a long and winding one, but progress is being made, slowly but surely. As the International Bar Association's Tim Hughes said recently in Geneva, speaking of the 2010 U.N. resolution and what has been happening since, "That soft law is on its journey to becoming hard law."