

FOR THE Elimination OF Leprosy

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



This photo of Nuriah, a person affected by leprosy in Indonesia, was taken by Budi Yuwono, who is the subject of Human Story on page 4.

MESSAGE

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Leprosy and NTDs

Recently the WHO has been putting greater efforts into the fight against neglected tropical diseases, or NTDs. Private foundations, pharmaceutical manufacturers and other partners are also becoming more active in this field. I warmly welcome this development.

But I have one reservation, and that is the term “neglected tropical diseases” itself. This represents the standpoint of experts and donors. People living with these diseases around-the-clock cannot forget their condition even for a second. I believe it is disdainful of those seeking to come to their aid to call these diseases “neglected.” As long as there are patients who are suffering, there should be no such thing as a “neglected disease.”

While it is wonderful that so many donors are now joining the fight against NTDs, joint efforts with the governments of the developing countries concerned will be a must. But 30 years ago, when I first started working for leprosy elimination, my insistence that it was essential to cooperate with individual governments placed

me in a minority. Back then many NGOs were not inclined to work with corrupt third-world governments, and my efforts attracted criticism.

But public health problems only get solved by concerted efforts based on mutual cooperation among the WHO, the governments concerned, NGOs and other stakeholders. Vindicating my assertion is the fact that we are drawing near the day when leprosy will have been eliminated as a public health problem in every country in the world.

The elimination of leprosy is a remarkable public health success story not seen since the eradication of smallpox. I believe it serves as an excellent example for stakeholders who are aiming to eliminate other NTDs besides leprosy.

But there are still many challenges to overcome. Every year, some 200,000 new cases of leprosy are diagnosed. For the rest of my life I intend to redouble my efforts to root out the disease and fight the stigma and discrimination it causes.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Progress in New Delhi

Symposium brings into clearer focus ways to implement Principles and Guidelines.



Guest of honor: Shri Mukul Balkrishna Wasnik, India's Minister of Social Justice and Empowerment, addresses the symposium.

New Delhi was the venue for the second in a series of five international symposia on leprosy and human rights, exploring ways to implement Principles and Guidelines on the elimination of discrimination against people affected by leprosy and their family members.

Building on the first symposium held in Rio de Janeiro in February, the October 3-4 gathering brought together some 200 participants from governments, UN agencies, NGOs, human rights groups, the media and organizations of persons affected by leprosy. Speakers included India's Minister of Social Justice and Empowerment, as well as three members of India's parliament, who announced the formation of cross-party forum on leprosy (see page 8).

With a focus on Asia, the symposium looked at the roles to be played by governments, NGOs, and people's organizations in implementing the Principles and Guidelines, which were adopted as part of a non-binding UN General Assembly resolution in December 2010.

Various government initiatives were held up, such as Thailand's steps to transform leprosy colonies into ordinary communities. The positive impact that NGOs can have was illustrated by the example of JIA, which organizes work camps in leprosy recovery villages in China. As for the part that people's organizations can play, suggestions ranged from translating the Principles and Guideline into local languages, so as to build awareness at the grass roots, to taking responsibility for monitoring the actions of governments. This latter role was illustrated on the second day, when members of the National Forum India posed questions to a bureaucrat from the Department of Disability Affairs.

While recognizing that a convention on leprosy would carry more weight than Principles and

Guidelines, speakers said there were still plenty of channels to exploit.

"There's no need to reinvent the wheel," said Javed Abidi, the chairperson of Disabled People's International. "A convention on leprosy may be a worthwhile long-term goal, but until that happens we need to ensure that we benefit from existing systems that are in place." Examples he put forward included the Committee on the Rights of Persons with Disabilities — "which must be sensitized to ask questions about leprosy whenever a nation comes before it" — and the Universal Periodic Review, the mechanism by which countries are vetted on their human rights record.

Another speaker made the case for utilizing the International Labor Organization. Dr. Anwar Ahmad Rashed Al-Fuzaie said that Convention 111 on discrimination in respect of employment and occupation was one of the most important conventions in the ILO system and could be used to tackle discrimination on the grounds of leprosy.

INTERNATIONAL WORKING GROUP

The symposium also saw the first meeting of an International Working Group (IWG), tasked with formulating plans of action and a mechanism to monitor actions taken by states and other actors.

IWG member Professor Mariko Akuzawa said an advisory committee had met several times in Japan in the run-up to Delhi, but that the discussions had been "rather theoretical." Having people with international perspectives joining together different ideas at the IWG made it much more real, she said. She also praised the symposium for its broad composition of stakeholders and the participatory nature of the process.

The third in the series of symposia, which are being supported by The Nippon Foundation, is planned for the first half of 2013 in Africa. ■

A Date with the Dalai Lama

His Holiness the 14th Dalai Lama shares a message that all of us should heed.

AUTHOR:

Yohei Sasakawa

Yohei Sasakawa is chairman, The Nippon Foundation, WHO Goodwill Ambassador for Leprosy Elimination and Japanese Government Goodwill Ambassador for the Human Rights of People Affected by Leprosy.

In late August I traveled to northern India for an appointment with His Holiness the Dalai Lama in Dharamsala. I have met the Dalai Lama on previous occasions. He has been a great supporter of my annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, endorsing it in 2006 and again in 2009.

On this occasion, he had kindly agreed to record a video message. I believe his words will help to bring closer the day when we can live in a world free from leprosy-related stigma and discrimination.

As we talked, he told me of a visit he had made to see the late Indian social activist, Baba Amte. Baba Amte had set up an ashram for the treatment and rehabilitation of people with leprosy in Maharashtra state. What impressed the Dalai Lama most, he told me, was how everyone there lived with self-respect.

He also mentioned a visit he had made to Orissa state some 20 years ago with his brother. At the time, they were told some half a million people with leprosy lived in Orissa. "It is quite encouraging that the number of patients in India has now come down. That is good news. Wonderful," he said.

But on the topic of lingering discrimination, he noted there was still much that needed to be done. "It is not good that people continue to be discriminated against even after they are cured. These things are social habits. We must change them. In order to effect change, we must make an effort," he said.

He suggested there was role for religious leaders to speak out and reassure their followers that people affected by leprosy pose no threat and there is no reason for them to be isolated, "which is totally wrong."

"If society rejects a person affected by leprosy, then society is losing one member of society," the Dalai Lama said.

'BROTHERS AND SISTERS'

In the video message he recorded in my presence, the Dalai Lama said, "Seven billion human beings are essentially brothers and sisters. We are born the same way and we die the same way. Everyone wants a happy life and has the right to achieve a happy life."

"We are social animals," he continued. "Each individual's maximum happiness remains within society as a member of the community... Any social animal, one single being, when separated from the community of the group, is unhappy."

The Dalai Lama said it is important for people affected by leprosy to be accepted by the rest of society as part of the human family. "That is the human way, and spiritually speaking also, it is a real act of compassion."

"Seven billion human beings are essentially brothers and sisters," the Dalai Lama said.

He also noted that while people are always talking about love and compassion, these sentiments are often betrayed by unnecessary discrimination. People of religious faith must live according to what they profess, he said. Even those who do not believe, as members of the seven billion-strong human community, must reach out to every other human being. "At a human level, it is, I think, a really important practice of secular ethics," he said.

I feel certain the Dalai Lama's message will touch many people. I, for one, left his presence inspired — and determined to work even harder to bring about a world without leprosy. ■



In 2009, the Dalai Lama joined other faith leaders in signing the Global Appeal.



In order to effect change, we must make an effort, the Dalai Lama told me when we met on August 27.

Budi's Journey

How a patissier became a photographer via a diagnosis of leprosy.



After graduating from high school in my hometown of Malang, East Java, I enrolled in the Bali Tourism Institute to study cooking and pastry-making. I wasn't that interested in studying or getting a job; I just thought it would be fun to go to Bali.

But once the course began, I became interested. I applied myself and it seems I had a talent for it. I was chosen to go for six months' training at a five-star hotel in Singapore.

Eager to see more of the world, I applied for a job with Carnival Cruise Lines. I spent two years in the Caribbean, followed by six months in Europe. Although working aboard ship was hard, I really liked being able to visit so many different places.

FIRST SIGNS

In 2008, while I was in Europe, red patches began to appear on my body. At first I thought it was some kind of allergy. I went to several different skin specialist but they weren't able to identify what was wrong. I was given some prescription drugs, but they didn't help.

Over time, the number of patches on my body increased and I became concerned. I quit my job and returned to Indonesia. I went to various different skin specialists, but it wasn't until I visited a health center in Surabaya, East Java, that I was diagnosed with leprosy. A doctor there had studied under Professor Indropo, who was an authority on the disease.

DARK DAYS

It was a tough time. I didn't have a job and my fiancé's family forced me to break up with her after I told them about the disease. I was so depressed I shut myself away at home.

To pass the days, I taught myself photography. I began by taking pictures using a low-end digital single lens reflex (DSLR) camera. Photography has since become a big part of my life.

Something else helped me through this difficult period: PerMaTa, the NGO started by people affected by leprosy to improve their quality of life and fight stigma and discrimination. I was introduced to PerMaTa by Dr. Diana Liben, who was helping me while I was on MDT. A dermatologist based in Surabaya, she is a mother figure to people affected by leprosy.

Encouraged by Dr. Liben, I went along to one of their meetings. I met people in similar circumstances to my own, which felt like gaining a whole new family. I rediscovered my desire to live and decided I wanted to help others who, like me, had shut themselves away because of leprosy. Now I work as PerMaTa's program manager.

"Just believe that God has other beautiful plans for us besides this leprosy."

ARTISTRY

Because my job with PerMaTa is getting busier, I don't have that much time for photography, but I still enjoy it. These days I mostly photograph models, but I've also undertaken plenty of assignments — everything from weddings to kids' birthdays and commercial shoots.

Photography is painting with light. It's important to me because it allows me to express my artistry. In that sense, it's similar to being a patissier: you need a sense of artistry, otherwise your work will be empty.

Looking to the future, I'd like to get married, be a good husband, start my own business and make my wife and children happy. I will also continue working on behalf of people affected by leprosy for the rest of my life.

The chance to meet so many "family" has been one of the most rewarding aspects of joining PerMaTa. As I tell people affected by the disease, "Just believe that God has other beautiful plans for us besides this leprosy." ■

AUTHOR:

Budi Yuwono

Budi Yuwono is program manager of PerMaTa, an Indonesian NGO formed by people affected by leprosy.

FOOTNOTE

Budi was the photographer for *Merajut Harapan* (PerMaTa 2011), featuring inspiring stories of people affected by leprosy such as Nuriah (page 1) and Augustina (below).



Fighting for Human Rights

Tamara Biolo Soares brings passion to her work of combating discrimination.

PROFILE:

Tamara Biolo Soares

Tamara Biolo Soares is head of the Department of Human Rights and Citizenship of the Department of Justice and Human Rights of Rio Grande do Sul State, Brazil.

Tamara Biolo Soares attended the recent New Delhi symposium on Leprosy and Human Rights, where she took part in the first meeting of the International Working Group to formulate plans of action and a monitoring system for implementing Principles and Guidelines for ending discrimination against persons affected by leprosy and their families. She shared her thoughts on the sidelines of the meeting.

How are you enjoying the symposium?

It's a unique moment to share both knowledge and experience, a moment we usually lack given our crazy schedules. The opportunity to be part of the International Working Group, drawing up a plan of action and being part of a process of building up a monitoring system, is also a wonderful one.

What issues does your state face with regard to leprosy, or Hansen's disease?

My state is the only state in Brazil with a low incidence of Hansen's disease, but we still have the issues you find all over the country. The other day, at a public hearing we held, there was testimony from a young lady whose mother had the disease. The daughter had been working at a firm for two years when she told a colleague. Within a few months she was fired. This is what the second generation has to deal with. If they mention they lived in a colony or are sons and daughters of persons affected by leprosy, they will face discrimination. They will lose their jobs and their communities. We are still concerned with late diagnosis, but social stigma is probably the biggest challenge that we have right now.

Have you heard anything at the symposium that has caught your imagination?

There was a statement from a Japanese expert about the impact that a museum has had in raising awareness about the disease. As a government, we are thinking about strategies to raise awareness. For example, we have engaged the first lady of my state in the fight against discrimination; she visited a colony, which was wonderful. We are thinking about how to share with society the knowledge that the disease is curable and there are no possible grounds to discriminate. Maybe there is role for a museum or similar.

How important is the role of the public sector in combating discrimination?

I believe the public sector has a huge role, but not only the public sector; it is a shared responsibility. I also believe we need affirmative actions to achieve de facto equality. It's not enough to abolish laws.



Tamara Biolo Soares: her state is setting an example

How much of your department's work concerns Hansen's disease?

I'm head of the department of human rights and citizenship. We are proud of the fact that in every policy we have, we take into account the views of the people concerned — women, children, the elderly, Afro-Brazilians,

or in this case persons affected by Hansen's disease. Currently we don't have a specific department for leprosy, but the issue has been gaining attention. Historically in our state, the health secretariat would oversee Hansen's disease; now there has been a little bit of a shift to dealing with leprosy as a human rights issue, which is an achievement.

Is your state ahead of other states?

Very much. We are setting the example. Now one of my goals is to present to our representatives a proposal that the Principles and Guidelines become state law. That would be something that would pave the way for other states to do so as well. We have already started a conversation with a few representatives. They were really interested and we had a public hearing. We might be able to approve it as a state law.

One of my goals is to see the Principles and Guidelines become state law.

How did you get interested in this issue?

I'm a lawyer. I've always worked in human rights; specifically, the issue of discrimination. For my Master's thesis I studied the discrimination suffered by second-generation Haitian immigrants in the Dominican Republic. Given my interest in the second generation and indirect discrimination, the path to Hansen's disease was not so long.

Was there a particular case that got you started?

Yes, the case of the young woman that I mentioned. I first heard her testimony a year and a half ago, and it had a huge impact on me. This lady cries every time she talks about it. It is not an isolated case. ■

9 Days in India

Dharamsala, Delhi and Bhopal were on the Goodwill Ambassador's itinerary when he visited India recently. He also welcomed another visitor to Japan.

INDIA (AUGUST 25-SEPTEMBER 2)



View of Dharamsala

In late August I traveled via New Delhi to Dharamsala in the north of India to meet with His Holiness the Dalai Lama. It was an inspiring meeting that I recount elsewhere in this issue (see page 3).

During my stay in Dharamsala, I called at the Palampur Leprosy Home and Hospital. Founded by Christian missionaries in 1917, it has 17 residents. A number of them followed the Dalai Lama from Tibet. It is in a beautiful setting. "We have a good life here," one elderly man told me. "There is no discrimination."

Returning to New Delhi, I had a meeting with leaders of the National Forum India (NFI), the nationwide forum of people affected by leprosy that I helped to establish in 2005. Since our last meeting, there had been a change at the top. Dr. P.K. Gopal, the founder and chairman of the forum, is now senior consultant.

The new chairman is Vagavathali Narsappa, the former president of the Society of Leprosy Affected Persons in Andhra Pradesh. Mr. Narsappa told me he intends to make full use of the experience he has gained at the grassroots.

Together we called on Union Health Secretary P.K. Pradan and the WHO's regional director for Southeast Asia, Dr. Samlee Plianbangchang. I also had a meeting with the Sasakawa-India Leprosy Foundation (SILF) as well as a number of media interviews before we flew to the state of Madhya Pradesh on August 30.

In 2011, Madhya Pradesh recorded 5,858 new cases of leprosy out of 127,295 cases for India as a whole. The leprosy prevalence rate in the state is 0.63 per 10,000 people.

My mission was to learn about the situation on the ground and seek a commitment from political leaders to improve living conditions of people affected by leprosy, including the provision of a bigger pension.

At the time of my visit, people affected by leprosy living in colonies were receiving a pension of just Rs. 150 per month. The average in other states is around Rs. 500 rupees; in Delhi it is as high as Rs. 1,800.

Together with NFI Chairman Narsappa, NFI Trustee and State Leader Sarang Gaydhane and members of the Madhya Pradesh Leprosy State Leader Committee, I called on Chief Minister with Shivraj Singh Chouhan. Mr. Gaydhane presented the chief minister a letter requesting the government to improve conditions of leprosy colonies along with a survey report on colonies in the state. While health department records show only 10 colonies, Mr. Gaydhane's report lists 34 leprosy colonies in 17 districts that are home to 3,761 people.

I told the chief minister about developments on the pension front elsewhere in India. I cited the example of Bihar, which has agreed to raise the monthly pension for people affected by leprosy from Rs. 200 to Rs. 1,800. I requested that he look into the possibility of raising the pension in his state, too.

On the spot, the chief minister promised to increase the pension to Rs. 1,000 and said he would respond appropriately to Mr. Gaydhane's other requests, including the building of sub-health centers and improvements to colony housing.

Afterward, following a meeting with Justice A.K. Saxena, the acting chairman of the state human rights commission, I held a press



Mr. Narsappa chats with Dr. Plianbangchang



Alongside Mr. Sarang Gaydhane following the meeting with Madhya Pradesh's chief minister

conference attended by some 30 journalists. I announced that the chief minister had promised to increase the pension and this was widely reported the next day.

To make the pension increase a reality, there is a process to be followed and more negotiations will be required. I will do what I can to support Mr. Gaydhane and his team to realize this outcome.

On August 31 I traveled three hours by road from the state capital Bhopal to the town of Indore. En route I stopped at Magaspur colony to visit a dairy farming project financed by a loan from SILF. The enterprise produces around 20 liters of milk a day, which is sold wholesale to the government and other entities. The group of four people involved receives a monthly income of approximately Rs. 18,000. They told me this enabled them to have a good quality of life and that they were very happy.



All smiles: nursing student Kalavati Wasuniya

Next I visited Ram Avtar colony in Alwasa. SILF has financed agricultural projects that employ 30 people on land loaned by the government. I also met a young woman who is training to be a nurse with a scholarship from SILF.

Finally I reached Mr. Gaydhane's colony in Indore, where I took part in an assembly of about 100 residents. Children greeted me with a song and I met students who have received scholarships from LEpra for higher education. I could feel the positive energy the colony residents radiated. They have a good leader in Mr. Gaydhane and I applaud his efforts to improve the lives of people affected by leprosy throughout his state.

JAPAN (SEPTEMBER 11)

Recently I had the opportunity to meet with Mr. Jan van Berkel, the director of Netherlands Leprosy Relief (NLR), when he visited Tokyo in September. We talked about the current state of leprosy control, the challenges that remain and the importance of working together to achieve our common goal of a world without leprosy and its consequences.

Mr. van Berkel told me that NLR is focused not only on disease control, including diagnosing the disease before disability sets in, but also on rehabilitation in all its aspects, and social inclusion. "Every person we can prevent from suffering from disability, from stigma and from isolation represents a life gained," he said.

Based in the Netherlands, NLR relies primarily on Dutch citizens donating small amounts of money for its funding. But with Europe going through a difficult time economically, NLR is looking at the possibility of raising funds locally in some of the countries where it has offices, such as India and Indonesia. As well as easing the pressure on NLR's budget, Mr. van Berkel said, "I think that developing fund-raising programs in these countries may contribute to a civic commitment to these issues from their citizens."

Another topic that came up was chemoprophylaxis. NLR research has shown that the number of cases of leprosy among contacts of confirmed cases was reduced by half after two years, compared to a control group, if they were given a dose of rifampicin. Now NLR is experimenting to see if chemoprophylaxis can be rolled out on a large scale in one place, with the same effect. If the results of this pilot study in Madura, a leprosy-endemic island in Java, are successful, NLR would like to see chemoprophylaxis rolled out in every leprosy-endemic area.

I appreciated Mr. van Berkel's visit and shall be following NLR's activities with interest. ■

Indian MPs Take the Initiative

Announce formation of cross-party committee to study leprosy.



Minister of State for Human Resources and Development Dr. D. Purandeswari, flanked by MPs Dinesh Trivedi (left) and Madhu Goud Yaskhi (right)

Indian parliamentarians have formed a group to look into the issues facing people affected leprosy. MP Dinesh Trivedi, accompanied by Dr. Daggubati Purandeswari, Minister of State for Human Resources and Development, and fellow MP Madhu Goud Yaskhi, explained the initiative at the recent International Symposium on Leprosy and Human Rights held in New Delhi on October 3-4.

Saying that the only way to get rid of the stigma attached to leprosy is knowledge, Trivedi declared, “It is very important for people like us to spread this message of awareness.”

The new group, which cuts across regional and party lines, will brief itself on the disease and look

at what it can do, “including, if needs be, having a huge education campaign around the country,” said Trivedi.

“As people in the public domain — legislators, members of parliament — we have a huge responsibility because whatever we do is for the people,” he said.

Dr. Purandeswari said, “We have to look beyond leprosy as a medical and health issue and take an intersectoral approach. We should raise the issue of the intersectoral connectivity (of leprosy) within the parliament itself.”

She also brought up the part the media can play. “We know that the media had a large role when it spoke about how HIV/AIDS should not be stigmatized and how we need to get people into mainstream society. It’s the same proactive role that the media need to take when it comes to leprosy as well. That will help in addressing so many issues,” she said.

Ram Naik, former Union petroleum minister, who was in the audience, said he hoped the new forum would use its influence to help realize the implementation of recommendations contained in a petition he first submitted to parliament in 2007. The recommendations, which relate to various ministries, concern the empowerment of persons affected by leprosy.

The former minister said he would be happy to assist the new forum in any way. ■

FROM THE EDITORS

WHAT ARE HUMAN RIGHTS?

At an international symposium on leprosy and human rights in New Delhi recently, participants were reminded that the concept of human rights may need to be explained. “I’ve heard a lot of talk of human rights today, but people in colonies don’t know what human rights are,” said Ghasiram Bhoi, who heads an organization of persons affected by leprosy in India’s Chhattisgarh state.

Not knowing their rights means that people don’t know what to do about their rights, experts noted. “We don’t get complaints, because people affected by leprosy don’t realize these are human rights issues as well — they complain to the works ministry, (for example),” said Cecilia Quisumbing of the Philippines’s

Commission on Human Rights.

States, for their part, often do not understand the concept of protecting human rights as a state obligation. Moreover, they may need reminding that the burden rests with them to investigate violations of human rights, the UN University’s Dr. Vesselin Popovski said.

Raising awareness of UN-adopted Principles and Guidelines to end discrimination against people affected by leprosy and their families was the purpose of the New Delhi symposium. In the process, it also raised awareness that more needs to be done to explain the concept of human rights to those who will benefit from that knowledge and to those with a duty to respect, protect and fulfill those rights.

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