

# FOR THE Elimination OF Leprosy

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



(From left) JCI President Paschal Dike, Roshni, Ramavarai Sah and Hilarion Guia read aloud the text of Global Appeal 2016 in Tokyo on January 26.

**MESSAGE**

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## Tapping the Power of Youth

The 11th Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was launched from Tokyo on January 26 with the endorsement of Junior Chamber International (JCI), the international network of young businesspeople.

Most countries have seen a sharp drop in leprosy in recent decades, but the disease remains a serious concern in remote regions, ethnic minority areas where drug delivery is difficult, urban slums and other so-called hotspots. Meanwhile, people affected by leprosy and their families continue to face discrimination.

It is hugely encouraging, therefore, that an organization such as JCI, which energetically engages in a variety of causes, has turned its attention to leprosy and committed to participating in activities to end the discrimination. JCI President for 2016 Paschal Dike, who is from Nigeria, said he was shocked when he learned about the history of leprosy and the current realities, and said it was only proper for young people to get involved. "We

have the potential to promote change and have a big impact on society. When we are aware of the need, we act," he said.

A symposium followed this year's launch ceremony, with one of the sessions on health and human rights. In addition to people affected by leprosy, panelists included those representing intellectual disabilities, albinism, HIV/AIDS, and the deafblind. Although each situation is different, discrimination is a universal theme of human society, and overcoming it begins by understanding the suffering and hardship of those affected. "Nothing about us, without us," quoted one of the panelists. In other words, it is the people affected who know about their lives and the problems they face, and what the solutions are.

It is my hope that, inspired by knowing the tragic history of leprosy, members of JCI, especially those in developing countries, will passionately commit themselves to activities to help end discrimination.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Looking to the Young Generation

Global Appeal gets a youthful shot in the arm from Junior Chamber International.



Current and past signatories of the Global Appeal are among those sharing the stage with Japan's prime minister (center).

Harnessing the power and passion of youth in the fight against leprosy-related discrimination, Global Appeal 2016 was launched at a ceremony in Tokyo on January 26.

Junior Chamber International (JCI), an organization of young people aged between 18 and 40 with 200,000 members in 130 countries, became the latest organization to endorse the annual appeal, which calls for an end to the stigma and discrimination that people affected by leprosy continue to face.

Goodwill Ambassador Yohei Sasakawa, who initiated the appeal in 2006, said he had been keen to involve the younger generation, hence his delight that JCI had agreed to collaborate. "JCI members are the future business leaders of the world and are actively involved in community issues," he told the audience of 250. "I am very hopeful that opportunities to think about leprosy in different countries and regions will increase."

**I am challenging our members to act — not to wait for other people to find the solutions.**

JCI president for 2016 Paschal Dike from Nigeria said, "The philosophy of JCI is that young people have the potential to create significant impact in their communities and around the world." By signing the Global Appeal, he said, JCI was creating awareness among its members that people affected by leprosy are still being discriminated against in various parts of the world, and encouraging them to find solutions.

"I am challenging our members to act — not to wait for other people to find the solutions, but to take the initiative and just act," he said.

## GOVERNMENT SUPPORT

The ceremony was held in Tokyo for the second year running and once again Japanese Prime Minister Shinzo Abe and his wife, and Minister of Health, Labour and Welfare Yasuhisa Shinozaki, showed their support for the appeal by putting in an appearance. Noting that Japan's past policies had forced people with leprosy into isolation and infringed on their human rights, the prime minister expressed his hope that the Global Appeal would be an opportunity for people around the world to gain a proper understanding of leprosy and take action to eliminate prejudice and discrimination. "We have to learn from the past so that we do not repeat the same mistakes over again," he said.



Abe: "We have to learn from the past."

Representatives of organizations supporting past appeals, including the International Bar Association (IBA), International Council of Nurses (ICN) and World Medical Association (WMA), also spoke. Tim Hughes, IBA's deputy executive director, said the IBA supports the

Global Appeal wholeheartedly.

"It is very clear to us that the discrimination faced by people affected by leprosy is a direct violation of the fundamental rights and dignities offered to all people under the Universal Declaration of Human Rights and therefore must be addressed with urgency. It is also clear to us that this discrimination is illegal in international law."

Representing people affected by leprosy, Hilarion Guia, chair of the Coalition of Leprosy Advocates of the Philippines, said that while substantial headway has been made in the fight

Photos: leprosy.jp

## QUOTE

"We will aspire for a world in which individuals affected by leprosy and their families can live free from discrimination and enjoy the same rights and opportunities as everybody else in order to reach their greatest potential."

— From text of *Global Appeal 2016*

against leprosy, “this success must not dull us into complacency because the battle is not yet over.” Later he joined JCI President Dike, Ramvarai Sah, a trustee of India’s Association of People Affected by Leprosy, and Roshni — a Sasakawa-India Leprosy Foundation scholarship recipient who goes by one name — in reading aloud the text of the appeal.

**TARGETING DISCRIMINATION**

Following the launching ceremony, an international symposium was held in the afternoon on “Discrimination and How to Prevent It: Lessons from Leprosy.” It began with a brief overview of the current leprosy situation, given by Dr. Erwin Cooreman, team leader of the WHO’s Global Leprosy Program.

“The data points to stagnation in leprosy control over the past five years,” he said. “This is a tide we need to turn with the involvement of all stakeholders and this is what our new strategy hopes to address in the coming years.”

This was followed by two panel discussions: “Health and Human Rights — Combating Discrimination” and “Views of Younger Generations — What We Can Learn from Leprosy.” (see following pages)

The final session was a talk event on “Leprosy, Discrimination and Religion — Is a New Civilization Possible?” featuring Fumihiko Takayama, a non-fiction writer, and Tetsuo Yamaori, director general of the International Research Center for Japanese Studies, with actress and novelist Yuri Nakae acting as facilitator.

Closing remarks were delivered by Professor Kenzo Kiikuni, president of Sasakawa Memorial Health Foundation, which acted as co-organizer of the event. Addressing the issue of discrimination, he echoed the comments of JCI President Dike earlier in the day when he issued a call for everyone to be part of the solution. “Knowing is not enough,” Professor Kiikuni said. “You have to act.” ■

**‘ECHOES OF SINGING VOICES’**



A song featuring words by Japan’s Emperor Akihito and music by Empress Michiko, inspired by a visit they made to a leprosy sanatorium four decades ago, was performed as a curtain-raiser to this year’s Global Appeal launch ceremony.

It was in July 1975 that the then

Crown Prince and Crown Princess visited Okinawa Airakuen, a sanatorium in Nago city in Japan’s southernmost prefecture, Okinawa. After making an offering of flowers at the chapel house, they toured the wards and spent time talking with patients and staff.

As the Imperial couple were leaving, the residents began singing a traditional Okinawan song of gratitude and farewell, called “Danjokareyoshi.” The song is often sung to see off departing ships.

The incident made such an impression on the Emperor that he later commemorated it in a poem written in the traditional “ryuka” style, which he titled “Utageo no hibiki” (Echoes of Singing Voices).

*Danjokareyoshi no utageo no hibiki  
Miokuru egao menido nokoru*

[Echoes of singing voices of Danjokareyoshi  
The smiling faces of those seeing me off still  
remain in my heart]

The poem was presented to the residents of Airakuen, who set the words to existing Okinawan folk melodies. Learning of their desire for a special melody, the Emperor recommended to the Empress that she compose a piece of music. With the cooperation of composer Naozumi Yamamoto, “Utageo no hibiki” was completed. At Yamamoto’s suggestion, the Emperor also added a second verse.

*Danjokareyoshi no uta ya wakiagatan  
Yuuna sakiyuru shima kimo ni nokote*  
[The island where the singing voices of  
Danjokareyoshi well up,  
Where flowers of yuna were blooming,  
remains in my soul.]

The song was released as a CD last November to commemorate the 40th anniversary of the sanatorium visit. It was recorded by soprano Yumiko Samejima, who kindly agreed to perform at the Global Appeal on a charity basis.

“It is a great honor to sing a song written and composed by Their Majesties the Emperor and Empress. I believe the song demonstrates their warm hearts. They are always on the side of the vulnerable and I respect them very much,” she said.

# Nothing About Us, Without Us

Panelists offer perspectives on discrimination and empowerment.

Viewing a common problem from different standpoints, six panelists discussed the challenges facing those with leprosy and other diseases, disabling conditions and health impairments in “Health and Human Rights — Combating Discrimination,” one of the sessions at this year’s Global Appeal event. (Comments have been summarized.)



*Klaus Lachwitz is president of Inclusion International, a global organization representing persons with intellectual disabilities and their families. A lawyer by profession, he described his role as a member of the drafting group for the Convention on the Rights of Persons with Disabilities.*

Our official representative at the United Nations was Robert Martin, a person with intellectual disabilities from New Zealand, and I was his legal assistant. He is a so-called self-advocate, which means he wants to speak up himself. He brought the practical examples of discrimination and I tried to transfer that into legal terms. That was a really good thing to do and I think it was very progressive. We have to listen to these people, and we have to serve them.

One of Martin’s key calls in New York was to abolish guardianship laws. Guardianship laws mean that someone else has the right to speak for, take decisions about and exercise control over another person, which is totally against human rights. Human rights mean you have personal dignity, autonomy and the right to speak out.

The convention was not written and negotiated by scientists and diplomats — it was drafted in partnership with disabled people. The main message was: ‘Nothing about us, without us. We are the experts; we know how life is and what our problems in daily life are.’

Intellectual disability is not a disease; it’s an impairment. The impairment itself is not the problem; the problems are the barriers these people meet.

*Ikponwosa Ero is the U.N. Human Rights Council’s first ever independent expert on the enjoyment of human rights by persons with albinism.*

Albinism is a genetically inherited condition that results in a lack of pigmentation or color in the hair, skin and eyes. Nowadays we prefer the term “person with albinism” to albino, because albino equates the person with the condition, and I’m



sure you can appreciate the problem with that.

The frequency of albinism varies by region. In North America and Europe, 1 in 17,000 have the condition; in Africa, it is usually as high as 1 in 1,000. In some aboriginal groups in the South Pacific and

South America, levels reach 1 in 70.

In 25 countries we know of, people with albinism are being attacked with knives and machetes for their body parts. There is a belief based in witchcraft that these body parts can bring wealth and good luck when used in potions. As a result, there have been hundreds of attacks, and they are still going on.

Health issues that people with albinism face include low vision, high sensitivity to bright light and skin cancer; skin cancer is the number one killer of people with albinism today.

Stigma is another problem. In Hollywood films, a person with albinism is often depicted as crazy. There is also a problem with name-calling. Devil, freak, ghost, monkey, or ape are actual dictionary names of people with albinism when you translate them from the local language into English. Discrimination can be overwhelming, but I’m finding that leprosy holds lots of lessons for albinism.



*Ramvarai Sah is a trustee of India’s Association of People Affected by Leprosy, or APAL.*

India achieved the goal of eliminating leprosy as a public health problem in 2005, but changing the mindset of the community toward the disease and clearing

up the misconceptions is still a big challenge before all of us. I have a family and my two sons have been educated, but I have undergone the experience of stigma and discrimination and lived an isolated life when I was young.

APAL was formed in 2011 for the socio-economic empowerment of persons affected by leprosy. Discriminatory laws still exist that deny our rights. Old people still have to beg. Civic amenities are not provided to leprosy colonies in the proper way. APAL’s representatives should be involved in the community and we need to contribute to shaping government programs.



*Yasuji Hirasawa is on the steering committee of Japan's National Hansen's Disease Museum. Diagnosed with leprosy at 14, he has lived in a sanatorium for 74 years.*

We became involved in the movement for human rights of all people with disabilities, including leprosy. We learned that

by getting together we would be able to achieve things beyond our imagination. But our disease had certain characteristics — the deformity was visible — and we faced many difficulties.

We decided not to get angry but to forgive those who discriminated against us. In my area, I got involved in city planning. Some local people were against the idea of having leprosy-affected persons involved. But since the 1950s we have worked together to think about what we should do.

**We deny fundamental human rights when we don't do things with people, but for people.**

We decided to create a forest. We planted trees one by one as a token of gratitude to local people who accepted us. We hope that this human rights forest will be passed on to posterity.

To take things forward in leprosy, we need to trust each other, because in the past patients were isolated in leprosaria. But those days are over and should never be repeated. It's a negative legacy of humanity but one we have to learn from and turn these experiences into positive ones.



*Steven J. Kraus is director of the Regional Support Team for Asia and the Pacific of UNAIDS.*

One of the things we use a lot in HIV/AIDS is the principle called GIPA — greater involvement of people living with HIV/AIDS — which is this concept of nothing for us,

without us. If I am honest, I think those of us in the U.N. probably have to keep relearning that lesson many times.

All of us have a vested interest in working with the communities. When we don't do that, we

do silly things — preventing people from having a healthy and satisfying sex life, from having their own families. We deny some of the most fundamental rights when we don't do things with people, we do things for people.

A lot of the stigma experienced by people living with HIV/AIDS is self-stigma and often it's because of what society puts on them. Individuals feel they are less than perfect, not worthy, that somehow something is wrong with them, when in fact all they are doing is living with a bacteria, with a virus, or with a genetic condition.

It is very important to affirm the love and goodness in the person. That empowers them to address stigma and discrimination, and prevention and treatment.

There need to be partnerships between governments, civil society and people living with the disease — and they have to be genuine partnerships, not token ones. As we move forward, we must do so in partnership with each other.



*Akiko Fukuda is secretary general of the World Federation of the Deafblind. A deafblind person, Fukuda also has multiple sclerosis and uses a wheelchair.*

Deafblindness is a physical condition and not the name of an illness. We are like a rare species of missing in the

world. Maybe you know of Helen Keller. She was one of the most famous deafblind individuals, but not all of us are Helen Kellers.

The needs of the deafblind are different from those with other types of disability, yet Japan has no category for deafblindness in welfare-related legislation. We are very isolated and I would say we are kind of excluded.

There are many people who are deafblind but because we have difficulty in communicating, getting around, and also in getting information, it is very hard to connect with each other, even among ourselves. That's why I say we are missing people; I actually am missing from the stage.\*

To overcome stigma, maybe what we need is a "medicine". Together I think we can create a new medicine. It could be learning; it could be sharing; it could be an international convention or legal instrument; it could be anything that we work on together.

We should work together and support each other together to move one step forward, or one step higher, to live a life that matters ■

Photos: leprosy.jp

**FOOTNOTE**

\* Lack of wheelchair access prevented Ms. Fukuda from joining her fellow panelists on the dais.

# Youthful Perspectives

Panelists suggest what leprosy can teach — and what young people have to offer.



Wong: former patients are “role models”

“I’m a direct descendant of former leprosy patients. This statement is unthinkable for many of my peers.”

So began Joyce Wong, one of five panelists who shared their views on what the younger generation can learn from leprosy and how young people can help to end the stigma during a session forming part of the Global Appeal 2016 launch program.

Wong grew up in Sungai Buloh leprosy settlement in Malaysia and said there seems to be an unspoken sense of shame among many of the second generation. They feel unsafe to share their parents’ medical background with their friends or even with their spouse. “But is secrecy the answer?” she asked.

By not coming out and proudly declaring they are descendants of leprosy patients, they are not doing justice to their parents for all their parents have been through, she said.

Former patients deserve to be respected for battling and surviving the disease, Wong said. “They are role models for the younger generation in times of adversity; they should be seen as fighters, not victims.”

Joy in Action organizes work camps in leprosy resettlement villages in China. The camps are designed to improve the living conditions of residents, but they also offer valuable life lessons for the student volunteers who take part.

As the students live and work alongside the villagers, they learn to appreciate other points of view and develop new ways of communicating that they can apply in different walks of life. “This experience is quite important for young people,” said JIA Project Manager Yan Xunfang. “They learn a lot together with the villagers. They are a team.”

Young people also have a unique power that can be utilized when they are exposed to issues such as poverty and discrimination, she said. “Coming face to face with challenges empowers them to make change,” Yan said.

Aki Yasuda took part in work camps in China as a student. She is now vice president of Wappiness, an NGO in India modeled on the work camp concept.

Focused on communities of people affected by leprosy, Wappiness combines elements of work camp, employment support and education. “Our slogan is ‘Think together, act together and grow together,’” she explained.

Out of the experience of working with people affected by leprosy has developed the bigger goal of changing society. “When we first started, we wanted to create a world without discrimination; but that’s just bringing the negative to zero,” said Yasuda. “We need to enter positive territory, where all people live fulfilling lives and respect each other’s human dignity.”

## ‘HERE TO LEARN’



Junior Chamber International (JCI), supporter of this year’s Global Appeal, was well represented in the discussions. JCI Brazil President Fernando Bildhauer admitted he was new to leprosy, but said he was here to learn.

“We are involved with a lot of sectors of society. I believe we can make a good commitment to make something happen in Brazil, motivate young people and create a sustainable impact. The first step is to teach JCI members about leprosy and the disease in Brazil, so later we can create a project.”

Olatunji Daniel Oyeyemi, president of JCI Nigeria, said young people have a critical role to play in his country and gave two examples of successful projects JCI has been involved with in the past year: a campaign for free and fair elections; and a campaign to raise awareness of lassa fever.

Speaking of leprosy, he said: “We can’t talk about this issue without talking about advocacy and enlightenment, getting young people involved and taking the message down to the grassroots. We have the numbers, the strength, the manpower, the network and the reach.” ■

Photos: leprosy.jp

## QUOTE

“As young people we can no longer just talk. It is not enough to create awareness; we have to act and make sure we go beyond doing what is symbolic. This is not the end of our interaction; this is the beginning.”

— Arrey Obenson, JCI Secretary General

# Getting People to ‘Think Leprosy Now’

A networking event, a “bibliobattle” and a photo exhibition focus minds on leprosy.



Some take-home messages from World Café

Under the banner of Think Leprosy Now, a number of side events were held in conjunction with this year’s launch of Global Appeal 2016.

On January 27, a networking event styled as a World Café was held at The Nippon Foundation building in Tokyo. Taking its cue from this year’s appeal, which was endorsed by Junior Chamber International, the theme of the event was “Things young people can do.”

The audience of around 70 people, many of them students, listened as the evening’s invited guests from Brazil, Ethiopia, India, Indonesia, Japan, Nigeria and the Philippines introduced themselves. The guests included people affected by leprosy, family members and supporters.

Next, each of the guests moved to a table representing their country, marked by a national flag. Participants then “visited” a country for 20 minutes, before traveling to two more countries during the course of the evening. During their stay in each, they learned more about the situation on the ground and discussed what role young people could play in helping to eliminate discrimination. As the ideas flowed, they were jotted down on slips of paper.

At the end of a productive evening, participants wrote down their suggestions for what actions young people can take, or what had impressed them most about their country visits.



Champion battler  
(Photo: leprosy.jp)

## BATTLE OF THE BOOKS

A “bibliobattle” is a concept originating in Japan in which presenters have five minutes to talk up a book, following which there is a Q&A with each of the presenters, or “battlers,” and then the audience votes on a “champion” book.

On January 31 in

Tokyo, five battlers presented books they had read about leprosy. The books included *An (Sweet Red Bean Paste)* by Durian Sukegawa and *Watashi ga suteta onna (The Girl I Left Behind)* by Shusaku Endo. In their presentations, they spoke about the impact the books had had on their lives and what impressed them about the characters.

The champion book was *Umarete wa naranai ko toshite* by Ryoko Miyasato. It tells the story of a girl whose parents are affected by leprosy and the hardships they faced, as well as her own struggles in education, marriage and family relations, and how she maintained her dignity throughout.

## PHOTO EXHIBITION



“Think about leprosy, think about people”

Natsuko Tominaga has been a photographer with The Nippon Foundation for 14 years. During that time, she has made numerous visits overseas with the Goodwill Ambassador, documenting his visits to communities of people affected by leprosy all over the world.

“Think about leprosy, think about people” is the title of a traveling exhibition featuring around 50 of her images ranging from India to Ethiopia. They depict the lives of people affected by leprosy and provide a window on a world unfamiliar to many, yet recognizable in the humanity of her subjects.

Tominaga’s work was complemented by images created in Japan by photographers Akira Kurosaki and Nobuyuki Yaegashi, who have spent years documenting the lives of sanatoria residents with whom they have formed close relationships.

Yaegashi writes: “For a person affected by leprosy to agree to be photographed means coming out and taking a step into society. It involves a huge decision, and photography is a way of backing them up. I want to show the strength they possess to survive a harsh life.” ■

# Miyazaki's Awakening

Film director reveals how a sanatorium and its residents influenced his art and outlook.

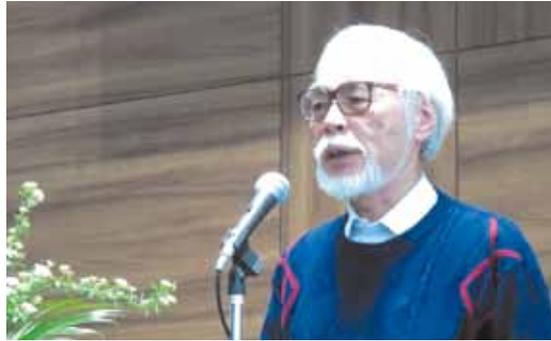
Celebrated film director Hayao Miyazaki was the guest speaker at the opening of a three-day international symposium in Tokyo at the end of January on leprosy history as a heritage of humanity.

Miyazaki, whose home is not far from National Sanatorium Tama Zenshoen in western Tokyo, described how his encounter with the sanatorium and its residents helped give shape to his 1997 animated historical fantasy *Princess Mononoke*.

At the time, he had the idea for a film that didn't feature samurai or nobles as the main characters, but showed the true face of the people — including beggars, outcasts and those with leprosy he had seen in old picture scrolls as part of his research. Setting foot in the sanatorium, those images came back to him and he knew there was no turning back.

Going to the sanatorium, paying his respects at the charnel house, visiting the museum, walking in the grounds and getting to know the residents became Miyazaki's ritual during the making of *Princess Mononoke*. He returned again and again.

These repeat visits and what he absorbed from them convinced him "there can be no question of doing things carelessly; I will make this film looking life in the face." The characters include metal workers swathed in bandages. He doesn't



Looking life in the face: Hayao Miyazaki addresses a symposium in Tokyo on January 28

shy away from the fact they have an incurable disease — a karmic illness, even — but said it was "imperative that I showed people, who, though suffering from a disease deemed 'incurable', tried to live with dignity and courage."

He is resolved to ensure that the hardships people affected by leprosy have suffered are never forgotten. As the population of the sanatorium declines, he has donated money to restore a former dormitory as a heritage site and is a supporter of preserving the "human rights forest" planted in the sanatorium grounds for future generations.

## WORLD LEPROSY DAY 2016

In its message for World Leprosy Day on January 31, the International Federation of Anti-Leprosy Associations (ILEP) called for proactive, early detection of leprosy to prevent the disease being transmitted to children and lifelong disabilities developing.

ILEP President Jan van Berkel said that "thousands of children affected by leprosy are not diagnosed early enough and as a result suffer from

preventable disabilities caused by the delayed diagnosis. We must improve our proactive, early detection of leprosy to prevent these tragic consequences."

In 2014, 213,899 new cases of leprosy were reported worldwide. Of these, the proportion of children accounted for 8.8%, and those with Grade 2, or visible, disabilities at time of diagnosis accounted for 6.6%. ■

## FROM THE EDITORS

### HUMAN EVOLUTION

There is increasing talk of distilling lessons from humanity's experience of leprosy to pass on to future generations. A panelist at the recent Global Appeal event in Tokyo neatly summed up what this means.

Joyce Wong was born to leprosy patients in Malaysia. She is intimately familiar with the isolation, fear, shame, stigma and discrimination

that surround leprosy, and the damage wrought by ignorance.

These are the things of which she spoke when she said: "Leprosy is a lesson that humankind has to learn for its own evolution. As with other catastrophes, it will keep repeating itself, maybe in another form, until we learn from it."

Has anyone put it better?

## FOR THE ELIMINATION OF LEPROSY

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