

FOR THE Elimination OF Leprosy

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



Japanese Paralympic swimmer Minami Ito performs at the launch of Global Appeal 2020 in Tokyo on January 27, 2020.

MESSAGE

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From Tokyo to the World

The 15th Global Appeal was launched from Tokyo on January 27, 2020, the day following World Leprosy Day. The annual appeal sponsored by The Nippon Foundation calls for an end to stigma and discrimination against persons affected by leprosy and their families and receives the endorsement of different influential organizations and individuals each year.

With Tokyo hosting the 2020 Olympic and Paralympic Games, this year's Global Appeal was supported by the International Paralympic Committee (IPC).

IPC's vision is to realize an inclusive society through Para sport. This aligns with the goal of the Global Appeal. As IPC Vice President Duane Kale said at the launch ceremony, ingrained attitudes and prejudices are among barriers to social inclusion. "Sadly, persons affected by leprosy encounter these attitudes daily and suffer discrimination in the same way as people with disabilities do."

Japan sees just a handful of cases of leprosy these days, but discrimination persists due to a nearly century-long policy of compulsory segregation that only ended in 1996.

In 2007, the Japanese government appointed me its Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy. Together with the government, I have been actively working to encourage the United Nations and the international community to restore the human rights of persons affected by leprosy. Out of these efforts came the 2010 UN resolution on elimination of discrimination against persons affected by leprosy and their family members.

Prime Minister Shinzo Abe, who also attended the two previous appeals held in Tokyo in 2015 and 2016, said on this occasion: "As a nation we have reflected on our history and provided support for the social rehabilitation of persons affected by leprosy, but the government will continue to do its utmost to eliminate the discrimination and prejudice that former patients and their families face."

With strong support from the IPC and the Japanese government, I believe that in this Olympic and Paralympic year of 2020, the message of the Global Appeal will resonate around the world.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Advocating Social Inclusion

International Paralympic Committee endorses latest Global Appeal from Tokyo.



Japanese Prime Minister Shinzo Abe (seated, center) joins the launch of Global Appeal 2020.

Goodwill Ambassador Yohei Sasakawa is hoping that this year's Paralympic Games will help promote a more inclusive society. That's why he was delighted to receive the backing of the International Paralympic Committee (IPC) for the latest Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy.

Launched from Tokyo on January 27 as the city prepares to host the 2020 Olympic and Paralympic Games this summer, the 15th Global Appeal draws on the power of the Paralympic movement to change perceptions of disability and difference through the performance of para-athletes.

Around 250 people joined the ceremony, including Japanese Prime Minister Shinzo Abe, Health and Welfare Minister Katsunobu Kato and Tokyo Organizing Committee head of the Olympic and Paralympic Games Yoshiro Mori.

INFLUENTIAL SUPPORT

Since the Global Appeal was initiated in 2006, it has received the backing of a wide range of influential individuals and organizations, including the World Medical Association, the International Bar Association, the International Council of Nurses, the Inter-Parliamentary Union and the International

TORCH-BEARER FOR THE APPEAL

Chandra Prakash Kumar, who flew from India to take part in this year's Global Appeal, has been busy since his return home talking about his trip to Japan and spreading the appeal's message of social inclusion.

Studying for a BA in hotel management in Mangalore, Karnataka state, Kumar is the son of parents affected by leprosy and grew up in the Little Flower leprosy colony in Bihar state. He is one of two children: his older brother has an MBA and works in the IT sector.

Following the Global Appeal, Kumar put together a PowerPoint presentation about his Tokyo trip—covering everything from visa requirements to the food he ate—and talked to his peers about Japan, leprosy and the need to build an inclusive society.

While still a schoolboy, Kumar helped out the family by working as a home tutor

in villages near his colony. At the time, there was a lot of prejudice and he was paid far less than other tutors, but he said he saw the experience as a golden opportunity to tackle discrimination head on.

"In the beginning, I felt people were keeping their distance, but whenever I got the chance, I tried to make them understand about the disease and I always got a positive result," he said. Over time, people started visiting his house and inviting his family to functions.

Kumar says he makes a point of reaching out to people wherever he goes—college classmates, lecturers, those he rooms with—to spread awareness and understanding of leprosy.

As a beneficiary of a scholarship program, he believes that education is a key to removing discrimination, as are livelihood



15回 グローバル・アピール2020
Kumar in Tokyo: spreading awareness

programs that wean people off begging and allow them to live a dignified life.

He often returns to his old colony during vacations, when he spends time talking with youngsters there, teaching, guiding and motivating them.

Following his trip to the Global Appeal, now he has another story to inspire them with—how a boy who grew in Little Flower came to share the stage with Japan's prime minister in Tokyo.



Global Appeal 2020 was the fifteenth appeal and the third to be launched from Tokyo.

Chamber of Commerce.

Each successive appeal has added to the voices calling for a world free from stigma and discrimination due to leprosy, underscoring the fact that only through a multi-sectoral approach will this be possible.

‘MEMORABLE YEAR’

As leaders of the Paralympic Movement, IPC brings to the appeal its vision of an inclusive world through Para sport and the Goodwill Ambassador said he looked forward to partnering with IPC “to fight all forms of discrimination in this memorable year.”

Representing the IPC at the ceremony in Tokyo was Vice President Duane Kale, a winner of four Paralympic gold medals in swimming for New Zealand, who said that the Tokyo 2020 Paralympic Games, with an expected cumulative TV audience of around 4.25 billion people, would be a huge opportunity to break down archaic attitudes and challenge stereotypes.

“Nobody in the world should face discrimination just because they are different.”

“Nobody in the world should face discrimination just because they are different, especially in the year of 2020. Every person on this planet should be free to live their life with dignity and enjoy all his or her fundamental human rights,” he said.

The ceremony also heard from Kazuo Mori, president of Japan’s National Council of Hansen’s Disease Sanatorium Residents, and Chandra Prakash Kumar (see sidebar), who was representing family members of persons affected by leprosy around the world.



Aspiring to a more inclusive society through Para sport: Yukinobu Ike (left) and Miki Matheson, who read out this year’s Global Appeal.

STAR PERFORMERS

The text of the appeal was read out by Yukinobu Ike, the captain of Japan’s wheelchair rugby team, and Miki Matheson, a three-time Paralympic gold medalist for ice sledge speed racing who now works as project manager at The Nippon Foundation Paralympic Support Center in Tokyo.

Another Paralympian, Minami Ito (cover photo), performed on the violin using a prosthetic arm designed for that purpose. Ito, who works as a nurse, was accompanied on piano by Koshi Kishita, known as “Japan’s Stevie Wonder,” and by sign-language performer Ichiro Hashimoto.

Prime Minister Abe, who was attending his third Global Appeal, said that the government had reflected on its past policies fostering discrimination against persons affected by leprosy and had offered apologies and reparations not only to persons affected but also now to their families as well.

Noting the backing of the IPC for this year’s appeal, he expressed the hope that, through the power of sport, the Tokyo Olympic and Paralympic Games will make 2020 a year in which we progress toward a society where “the dignity and fundamental freedoms of all people are respected.” ■

TEXT OF GLOBAL APPEAL 2020

*Leprosy is a curable disease.
But it is not just a simple health issue.
Many people affected by the disease are marginalized because of stigma and discrimination.
Their opportunities in life are restricted, even after being cured.
Society’s prejudice has a negative impact on their families, too.
The International Paralympic Committee aspires to a more inclusive society for people through Para sport.
It aims to challenge stereotypes and transform attitudes,
breaking down social barriers toward people with a disability.
Diversity and inclusion are core to what the IPC stands for.
We are committed to the creation of a just and equitable society.
In this Paralympic year 2020, we stand with persons affected by leprosy in calling for an end to stigma and discrimination.
Together we seek to realize a society that respects the human dignity and fundamental freedoms of all its members.*

Difference Is Natural

Roundtable discussion generates perspectives on the benefits of diversity.

With the International Paralympic Committee (IPC) endorsing this year's Global Appeal launched on January 27 in Tokyo, a roundtable discussion held earlier in the day explored the themes of diversity and inclusion.

Organized by Sasakawa Health Foundation, "Difference Is Natural" brought together a former para-athlete, a prosthetist and orthotist, the curator of a Hansen's disease museum, a journalist and a person affected by leprosy. The discussion was chaired by Professor Shigeki Sakamoto, president of Japan's Center for Human Rights Education and Training and author of UN Principles and Guidelines for eliminating discrimination against persons affected by leprosy and their families.



Giving the keynote address was Ms. Miki Matheson, a former para-athlete who works as project manager of The Nippon Foundation Paralympic Support Center in Tokyo.

She described two events in her life that have informed her views.

First was the traffic accident that left her no longer able to walk. As a result, using a wheelchair became natural for her. But in Japan's "conformist" society, she said, this made her different and attitudes toward her completely changed. "People began to treat me as a foreign object. This was more shocking to me than losing the use of my legs."

Second was moving to multicultural Canada following her marriage, introducing her to a more open, accepting society where difference *was* natural. She recalled being encouraged to visit her son's school as often as possible—she ended up volunteering to do different jobs there—because 'it's good for the kids to be exposed to people with different needs,' she was told.

"It's imperative to acquire the value that difference is wonderful and also the tools necessary to ensure fairness and justice," she said. "It's an urgent issue here in Japan."

CREATING THE RIGHT ENVIRONMENT

Yusuke Ono makes artificial limbs and assistive devices for a living, and provides counselling for people who have lost body parts. Each person has different needs, he pointed out, and an important part of his role is finding out just what these are and what difficulties a person encounters as a result of his or her disability.

One of his clients was no longer able to practice

the tea ceremony after losing a leg—until Ono was able to find a prosthetic that allowed her to sit in the formal manner and resume her hobby. "I try to create a comfortable environment for people with disabilities to express their needs easily and naturally," he said.



Tomihisa Tamura is a curator at National Sanatorium Nagashima Aiseien located on an island in Japan's Inland Sea. In the past, the sanatorium—one of 13 former leprosaria nationwide—was a symbol of the country's policy of forced segregation of leprosy patients. Cut off from the outside world, the sanatorium inmates were subjected to human rights abuses—among them compulsory sterilization.



Today the sanatorium and its museum attract more than 10,000 visitors a year, and Tamura is leading efforts to gain UNESCO World Heritage status for the site.

"Symbols change," Tamura said. "Look at Hiroshima. With the passage of time, the A-bomb dome has become a symbol of peace. Before, Nagashima Aiseien had a negative image. Now, it's a place to learn about human rights."

Tomoko Takaki started working as a journalist in 1996, the year Japan's Leprosy Prevention Law was abolished. Through her reporting she has explored why people with Hansen's disease were left behind by the rest of society.



"It was prejudice over their appearance, ignorance about the disease and a lack of interest in learning more. There was also societal peer pressure, resulting in their isolation over many years."

She admitted to having her own biases about the sanatoriums and their residents until she came to know them better through her work.

"In fact, people there live a normal life—and I was shocked to find that this surprised me. They

garden, they paint, they root for their favorite baseball team on TV.” What’s more, with the help of assistive devices and ingenious workarounds, they can flourish. “It is possible to be different, and to enjoy being different. If this notion resonates with society, society will be richer,” she said.

GOING PUBLIC

Speaking as a person affected by Hansen’s disease, Miyoji Morimoto, the former president of IDEA Japan and a long-time activist, remember being asked: “You’re cured. Why don’t you lead a normal life?” “It’s not that easy,” he replied. “The disease cuts you off from family. Just because you’re cured doesn’t mean you can suddenly re-emerge and cause them problems.”



But he felt a contradiction in himself: he was working for social inclusion, yet living under a pseudonym in a sanatorium. So, when the Leprosy Prevention Law was abolished, he decided to ‘come out’. He and his wife Mieko wrote a book under their real names and appeared on a popular TV show. “The impact was huge. It turned my life on its head,” he said.

More than two decades on, he feels that prejudice and discrimination are slowly lessening,

but acknowledges that the situation is complex. To illustrate his point, he cited a letter he received from a schoolboy. The boy wrote that he knew it was wrong to treat someone with Hansen’s disease or a disability as a lesser human being, but he felt superior because he was healthy and able-bodied. “I know it’s not right,” the boy wrote, “but I can’t help it.”

PROMOTING INCLUSION

Panelists had various suggestions for what is needed to promote acceptance of difference. Curator Tamura said they are working to make Nagashima Aiseien easier to visit. “We want to make the sanatorium a natural place for society,” he said.

Journalist Takaki highlighted the use of an island sanatorium as one of the venues for an international art festival in 2019, creating an opportunity for art enthusiasts to learn about the disease, and suggested that there should be similar initiatives in other fields, such as music, as a way to break down barriers.

For Morimoto, it was about opening the eyes of those who discriminate and “nurturing people who can put themselves in the shoes of the other person. For Ono, it was about empathy and imagination.

Elaborating on his approach, the prosthetist and orthotist said: “Clients sometimes tell me that I won’t be able to understand their pain because I’m not disabled, but I feel it is my job to try. I use empathy and imagination as I work,” he said. “Imagination is what it takes to build an inclusive society.” ■

EVERYONE HAS THEIR OWN ‘NATURAL’

Tatsuki Shimizu saw the advertisement for the roundtable discussion and knew he had to attend. Involved in a motorcycle accident during his freshman year of college ten years ago, he had a personal take on the topic of “Difference Is Natural” (*‘Chigau’ wo atarimae ni*) that he wanted to share with the audience.

Holding up a piece of brushwork he had composed, he explained what he meant by *“Atarimae/Sore ga igai to/Arigatai”* (What I used to think of as natural is actually something to be thankful for but which is also difficult to have).

“Since becoming disabled as a result of the accident, I can no longer do things I once took for granted,” he explained. “Consequently, I began to strongly question the difference between what I thought of as ‘natural’ when I was able-bodied and what is ‘natural’ now that I am disabled.

“When you are no longer able to do something that you took for granted, that’s when you appreciate it for the first time—and appreciate how precious it is.”

Shimizu took up calligraphy when he was in hospital. His first effort, pressed deep into the paper because of the difficulty he had controlling his right arm, consisted of the characters, *Koku ikiru* (Live deeply). The response to his handiwork encouraged him to continue.

“What I want to say is, everyone has their own ‘natural’.”



India Remains a Priority

The Goodwill Ambassador encourages India in its efforts against leprosy, witnesses the signing of an initiative to designed to improve employment prospects for persons affected, and visits the prime minister's home state.

INDIA (January 28 – February 4)

My 60th visit to India took me to the capital, Delhi, and the northwest state of Gujarat facing the Arabian Sea. As country with some 60 percent of the world's leprosy cases, the progress India makes will have a huge impact at the global level.

In Delhi I called on Dr. Harsh Vardan, the minister of health and family welfare, and Thaawar Chand Gehlot, minister of social justice and empowerment.

I told the ministers that I appreciated the efforts being made by India to tackle leprosy and the discrimination it causes.

As a way to accelerate those efforts, I asked them to consider setting up a coordinating committee within the central government that would cut across ministerial lines and deliver a comprehensive solution covering all aspects of the disease, both medical and social.

One task is to ensure there are opportunities for social and economic rehabilitation. Therefore I was delighted to take part in an event organized by Sasakawa-India Leprosy Foundation to mark India's Anti-Leprosy Day on January 30. The event was the occasion for the signing of a Memorandum of Understanding between S-ILF and the Confederation of India Industry (CII).

This was an initiative first proposed at the launch of Global Appeal 2019 in New Delhi last year, and will see CII partner with S-ILF in raising awareness of leprosy and improving prospects for employment through skills training and



The CII and S-ILF sign their Memorandum of Understanding as Health Minister Dr. Harsh Vardan (3rd from right) looks on.

livelihood programs.

At a separate event to mark the launch of my recent book *No Matter Where the Journey Takes Me*, I had the opportunity to chat with Minister of External Affairs Subrahmanyam Jaishankar, who said that the government was determined to realize a society free of leprosy and related discrimination.

The next day I departed for Ahmedabad, the capital of Gujarat state, the birthplace of Mahatma Gandhi and the home state of Prime Minister Narendra Modi.

Gujarat reported 3,410 new cases from April to December 2019. When Gujarat eliminated leprosy as a public health problem at the state level in 2004, 12 districts remained endemic. Since then, a combination of case-finding, awareness-raising, special activities in remote areas and the introduction of single-dose rifampicin for close contacts of confirmed cases means that eight out of these 12 districts have now achieved elimination. Dr. Grish Thakar, the state leprosy officer, told me Gujarat has set a target of 2022 for elimination across all districts.

There are 14 leprosy colonies in Gujarat. Up until a year ago, there had not been any coordinated activity among them; since then, the Association of People Affected by Leprosy (APAL) has begun advocacy work in the state.

During my stay I met with 60 Accredited Social Health Workers (ASHA) at Sanathan Public Health Center and 30 more at Chekhala Public Health Center. ASHA are active at the community level, checking for signs of leprosy and other diseases. They play a very important role in referring suspected new cases. I thanked them for the work they do and presented them with a flipchart about leprosy (see sidebar).



A welcome from young colony residents in Gujarat



Chatting with colony leaders during my visit to Gandhi Kusta Seva Ashram in Ahmedabad

The next day, I visited the Gandhi Kusta Seva Ashram in Ahmedabad. A colony formed by migrants from other parts of the country in the 1960s, it is currently home to 65 persons affected and their families. It is located next to an industrial area, where I was told that many young people in the colony work. Every Sunday, they get together to exchange information and hold study sessions. I detected a real enthusiasm among them to improve their circumstances.

On the day I visited, many people from other colonies were also present, having made the journey to see me. I urged them to work closely with APAL to ensure that all their needs were fulfilled.

During my stay in Gujarat, I had the opportunity to meet with senior state officials whose responsibilities touch on the lives of persons affected by leprosy. Among them were B.G. Nainvale, commissioner for persons with disabilities, Dr. Jayanti S. Ravi, principal secretary of health, Anil Mukim, chief secretary of Gujarat,

and Health Commissioner Joi Prakash Shivahare.

On these visits I was accompanied by APAL representatives in order for the government to hear directly from the people themselves about the issues that concern them most. As APAL's Vice President G. Venugopal told Chief Secretary Mukim, the circumstances in which some older people with disabilities are living is very difficult, and he requested a special allowance for them. He also asked that the issue of land rights be taken up, as uncertainty hangs over some communities concerning ownership of the land they live on.

While in Gujarat I had the chance to visit one of Mahatama Gandhi's former residences—the Sabarmati Ashram—which was his home between 1917 and 1930 during India's freedom struggle.

As a recipient of the 2018 Gandhi Peace Prize for my leprosy work, I am well aware that it had been Gandhi's dream to see India free of leprosy. This latest visit spurs me on to greater efforts to help India realize his vision. ■

GATHER ROUND THE FLIPCHART

When I visited India around this time last year, I handed out copies of the revised and updated *New Atlas of Leprosy* to ASHA (Accredited Social Health Activists) in Dadra and Nagar Haveli. This time, during my stay in Gujarat, I presented ASHA with a flipchart that describes in simple terms the symptoms and treatment of leprosy.

The illustrated flipchart is easy to follow and can be used by community health workers as a tool to raise awareness of leprosy and clear up some of the misconceptions people may have.

While most people now receive information via a mobile phone or a smartphone, there is something engaging about a flipchart, especially in the hands

of an enthusiastic health worker eager to put people's minds at rest about an often feared and misunderstood disease and see they receive prompt treatment.

The 16-page flipchart, a joint project of the health ministry, WHO and Sasakawa Health Foundation, contains two storylines. The first story involves Meena, a tailor, and Bubbly, "a dedicated ASHA," and explains what the symptoms of leprosy are, how it is diagnosed, and how it is treated. The second story features Tara, a beautiful woman getting ready for marriage, and cautions against ignoring discolored patches on the skin as the consequences can be life-changing.

The bottom line is, check your skin and that of your family regularly,



With a pair of ASHA in Gujarat as we pose with copies of the flipchart I presented them with earlier.

and seek advice if you find anything suspicious. It's a message I repeat all the time as Goodwill Ambassador, but not as colorfully as this flipchart does.

Special Rapporteur Visits Japan

Praises steps taken on Hansen's disease reparations, but highlights need for care of aging.

Alice Cruz, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, made an eight-day official visit to Japan from February 12 to 19.

During her stay, Cruz met with representatives of government ministries, civil society organizations, law and health experts, and persons affected by Hansen's disease and their families. She also visited the National Hansen's Disease Museum as well as sanatoriums in Tokyo and on Nagashima Island in Japan's Inland Sea.

Cruz commended the government for responding to the voices of affected persons by recognizing its responsibility for past violations of their human rights, offering a public apology and compensation, and putting in place a multi-sectoral approach to Hansen's disease. She also noted Japan is the only country to take up leprosy as a human rights issue at the international level.

But she highlighted the fact that 1,100 people with an average age of 86 still live in Japan's 13 national sanatoriums where they were once segregated by force, many of them living with physical and psychosocial impairments as well as disabilities related to Hansen's disease. "They still struggle to restore their dignity and their family ties broken by decades-long institutionalized discrimination," Cruz said.

"My strongest impression during this visit is



Cruz (right) at press conference in Tokyo

that even though people have felt some degree of restoration of their dignity due to the reparation measures and policies that have followed these measures, from what I heard the public apologies were much more important than the monetary compensation."

Cruz, who supports the application of Nagashima to achieve UNESCO World Heritage status, said preserving the history of Hansen's disease was important because the aim of past policy had been to "erase these people from history."

History preservation is necessary to restore the dignity of those who suffered violations, to ensure that systemic violations on the grounds of health conditions do not happen again, and to educate on human rights, she said.

"I believe we need to acknowledge this is a global history, so it makes a lot of sense to take this issue to the global level. This is important to all who wish to live in a decent society that respects our fundamental freedoms," she said.

Cruz will present her full report to the UN Human Rights Council in June 2020. ■

FROM THE EDITOR

JOINING HANDS AND HEARTS

World Leprosy Day, or World Hansen's Disease Day, on the last Sunday in January is an opportunity that many organizations seize to raise public awareness of the disease. This year, 17 people's organizations in different parts of the world carried out awareness-raising activities using a common logo and the tag line: "Hansen's Disease-Free World with Knowledge and Love".

From Ghana to Bangladesh, from Nepal to Mozambique, these grassroots organizations on Hansen's disease put together a series of actions and events that they shared on social media platforms, while also reaching out to local media organizations to raise the profile of leprosy.

Influential politicians, tribal chiefs, and celebrities took part. There were skin checks for schoolchildren and meetings with private healthcare providers

to sensitize them about the need to sustain the fight against the disease. Schools, mosques and churches played

host to talks on symptoms and the need for acceptance of persons affected by Hansen's disease. Radio phone-ins and TV appearances were helpful in busting myths about leprosy that have contributed to its stigmatization.

Central to these campaigns—from concept and planning to execution—was the role of persons affected by Hansen's disease themselves. It goes without saying, their slogan—a Hansen's Disease-Free World with Knowledge and Love—came from the heart.



Planning a campaign in Bangladesh

FOR THE ELIMINATION OF LEPROSY

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