

Leprosy and Human Rights – My approaches

By Yohei Sasakawa

Chairman, The Nippon Foundation

WHO Goodwill Ambassador for the Elimination on Leprosy

Japanese Government Goodwill Ambassador for the Human Rights of People
Affected by Leprosy

In June 2008, the UN Human Rights Council unanimously approved a resolution proposed by the Japanese government to end stigma and discrimination against people affected by leprosy. Coming in the 60th anniversary year of the Universal Declaration of Human Rights, this is an important breakthrough for people affected by the disease.

My first encounter with leprosy was in 1965, when I visited a sanatorium in South Korea. Seeing the poor conditions in which the patients lived had a profound effect on me. As a child, I lived through the firebombing of Tokyo in World War II, when 100,000 people died in a single night. When I looked back on that experience later in life, I came to believe that I had been spared for a reason, and decided to dedicate myself to ridding the world of injustice and improving the lot of society's weakest members. The visit to the sanatorium gave direction to this purpose.

The development of multidrug therapy (MDT) in the 1980s was a turning point in the fight against leprosy as it represented a truly effective cure. As a result, the World Health Assembly in 1991 set a goal of eliminating leprosy as a public health problem by the end of the 20th century. To give impetus to this endeavor, I pledged at the First International Conference on the Elimination of Leprosy, held in Hanoi in 1994, that The Nippon Foundation would provide MDT free of charge for five years from 1995. I believe this helped to instill courage and confidence in all involved in the elimination effort, and paved the way for the dramatic decline in the number of new cases.

Based on MDT, national governments, the WHO, ILEP members, local NGOs, health providers and others formed a robust coalition. Their dedicated efforts bore fruit. Between 1985 and the present day, the number of countries in which

leprosy is a public health problem (defined by the WHO as a prevalence rate of the disease of over 1 case per 10,000 population) has fallen from 122 to just three – Brazil, Nepal and Timor-Leste. This is a significant achievement, and can be seen as a milestone along the way to eradicating the disease altogether.

Unfortunately, however, where the social impact of the disease is concerned, discrimination against people affected by leprosy and their family members remains deep-seated.

In the long history of leprosy, a common response to the disease has been to cast out those afflicted from society. Once the symptoms appeared, it was as if a person ceased to exist. Abandoned by their own families, many were sent to facilities on remote islands or deep in the mountains, where they had no choice but to spend the rest of their days.

There were many mistaken beliefs about the disease – that it was highly contagious, hereditary, heaven's punishment – and these took root in the public mind. Because such beliefs are so deeply ingrained, people affected by leprosy continue to face social discrimination, even after they are cured. If family members are included, then the number of people who suffer from the stigma associated with leprosy probably runs into millions.

I believe that efforts to eliminate leprosy and leprosy-related discrimination have to take place concurrently. I often talk about this in terms of a motorcycle. If the front wheel represents medical activities, and the back wheel efforts to address the social issues, the wheels must be the same size and rotate at the same speed if the motorcycle is to move forward.

To remove the stigma and discrimination associated with leprosy from the world, I have put in place three strategies.

The first has been to focus attention on leprosy as a human rights issue by making political appeals to international organizations and national governments to take action. In July 2003, I approached the Office of the High Commissioner for Human Rights (OHCHR) and requested that the matter be taken up by the Commission on Human Rights. The following month, I made a presentation to members of the Sub-Commission on the Promotion and Protection of Human

Rights – the first time that leprosy has been raised as a human rights issue at the United Nations.

Next, in March 2004, the issue was put before members of the Commission on Human Rights, with the result that its Sub-Commission carried out a fact-finding survey. Based on the findings, the Sub-Commission unanimously adopted a resolution in August 2005 requesting that all governments act to end discrimination. A year later, in August 2006, the Sub-Commission approved a follow-up resolution.

In March 2007, the Japanese government indicated that it would take up the issue of the human rights of people affected by leprosy at the UN Human Rights Council, the body that succeeded the Commission on Human Rights. In September 2007, the Japanese government appointed me as its Goodwill Ambassador for the Human Rights of People affected by Leprosy and I have been working closely with the government ever since.

In June 2008, the Japanese government proposed a resolution eventually co-sponsored by 59 countries to eliminate stigma and discrimination against people affected by leprosy and their family members. On June 18, all 47 members of the Human Rights Council unanimously approved this resolution. This is the first time that so many governments have officially acknowledged that discrimination of this nature exists, and agreed to do something about it.

The resolution requests the OHCHR to collect information on the measures that governments have taken to eliminate discrimination, and to hold a meeting to exchange views with government observers, relevant UN bodies, specialized agencies and programs, NGOs, medical experts and people affected by leprosy. Based on what emerges, the Human Rights Council Advisory Committee is to formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and submit this to the Human Rights Council by September 2009. At last, the mountain is beginning to move.

My hope is that these basic principles and guidelines for eliminating discrimination will be approved by the Human Rights Council and transmitted to all UN member states. I would also like to see the Council propose a similar

resolution to be adopted by the UN General Assembly, as this would carry even more weight.

The second strategy has been to engage in awareness-building through a Global Appeal to End Stigma and Discrimination against People affected by Leprosy. Timed to coincide with World Leprosy Day on the last Sunday in January, the purpose of the appeal is to reach out to international organizations, national governments, media, opinion leaders, religious leaders and the public at large, and stress the need to clear up misunderstandings about leprosy while delivering the three messages that leprosy is curable, treatment is free and social discrimination has no place. The first appeal was issued in Delhi in January 2006. Jimmy Carter, the Dalai Lama and Desmond Tutu were among 12 world figures (including five Nobel Laureates) who added their signatures to mine. The second appeal, launched in Manila in January 2007 with enthusiastic participation by the people of the Philippines and its government, was signed by people affected by leprosy representing 13 countries. The third appeal, announced in London in January 2008 at the Royal Society of Medicine, was endorsed by nine leading international NGOs connected with human rights, including Amnesty International. I intend to continue with the Global Appeal until the UN General Assembly approves a resolution and basic principles and guidelines are embraced by all nations.

In addition to these two strategies, there is third, which is even more important. The third strategy is to support the empowerment of people affected by leprosy. To this end, I helped to establish a National Forum of people affected by leprosy in India, a country which accounts for approximately 70 percent of the world's new cases of the disease. The National Forum provides a common platform from which affected persons can speak out and make their voices heard, and upon which they can join together in actively working to reclaim their dignity and human rights.

One of my abiding memories of the first National Forum held in Delhi in 2005 is of an old woman who came up to me afterward and said, "I did not get the bag and shawl that were given to all delegates because I arrived late, but what I got today was something I never got in 30 years since I had leprosy: respect and dignity as a human being."

The National Forum has made great progress since it was started. In response to this burgeoning movement, the Sasakawa-India Leprosy Foundation has been established to support the social rehabilitation of people affected by leprosy via micro financing and scholarships, among other initiatives. Helping people affected by leprosy to help themselves is an essential part of the social empowerment process.

As the WHO's Goodwill Ambassador for the Elimination of Leprosy, I make repeated visits to countries and meet with presidents, prime ministers and national leaders. In our talks, I stress the three messages that leprosy is curable, treatment is free and that social discrimination has no place, and I urge them to make leprosy a priority. I also visit with front-line health workers to see the situation on the ground for myself, and spend time with people affected by leprosy to hear their views.

Another aspect of my work is to engage with the media. Spreading correct information about the disease and shaping public attitudes toward it are critically important. We cannot do without the media in this regard.

Please allow me to state my personal principles. What I want to see is the realization of social justice and the rehabilitation of marginalized people compelled to live on the peripheries of society. I am committed to helping those who suffer from poverty, hunger, and sickness, to protecting their basic human rights, and to seeing that they can enjoy a normal life. I make a point of visiting the people concerned, talking with them, and seeing the situation from their perspective. My belief is that where there are problems, solutions also exist.

We must continue to work toward a leprosy-free world – a world in which the number of cases of the disease approaches zero and in which there is no discrimination against people affected by leprosy or their families. To this end, I pledge to spend the rest of my life working with ILEP and other partners to achieve our common goal.

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