**ELIMINATION OF DISCRIMINATION AGAINST LEPROSY AFFECTED PERSONS AND THEIR FAMILY MEMBERS**

**Questionnaire for**

 **NON-GOVERNMENTAL ORGANIZATIONS**

**BACKGROUND**

In its resolution A/HRC/29/5, the Human Rights Council requested the Advisory Committee to undertake a study which reviews the implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, together with the obstacles thereto, and to submit a report containing practical suggestions for their wider dissemination and more effective implementation and to submit a report at its thirty-fifth session.

The resolution also requests the Advisory Committee, in its elaboration of the report, to take into account the views of Member States and as appropriate relevant international organizations, including the World Health Organization, the Office of the United Nations High Commissioner for Human Rights and relevant special procedures, national human rights institutions, and non-governmental organizations, as well as the work done on the issue by relevant United Nations bodies, specialized agencies, funds and programmes within their respective mandates.

In this context, the Advisory Committee decided, at its fifteenth session held in August 2015, to establish a drafting group in charge of the preparation of this study.[[1]](#footnote-1) The purpose of this questionnaire is to collect information from non-governmental organizations in order to identify the current state of implementation of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (the Principles and Guidelines); how the Principles and Guidelines apply to different situations in different countries, especially the good practices that may be shared; and the major obstacles to implementation, including views on how best to further strengthen the implementation of the Principles and Guidelines.

1. Are you aware of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010 (resolution 65/215)? If yes, how did it come to your attention?

Yes, we are very much aware of the Principles and Guidelines.

The Nippon Foundation has been tackling the issue of leprosy for over
four decades under the leadership of its chairman, Mr. Yohei Sasakawa,
who currently serves as the WHO Goodwill Ambassador for Leprosy
Elimination and Japanese Government Goodwill Ambassador for the Human
Rights of Persons Affected by Leprosy. It was Mr. Sasakawa who first
brought leprosy to the attention of the Office of the U.N. High
Commissioner for Human Rights in Geneva in 2003.

Since then we have worked consistently to focus the spotlight on this
important issue at the international level. We cooperate closely with
the Japanese government, which brought a request for action to the U.N.
Human Rights Council.  Accordingly, resolutions on elimination of
discrimination against persons affected by leprosy were submitted by the
Japanese government in 2008, 2009, and 2010. The Principles and
Guidelines which accompanied the 2010 resolution (unanimously adopted at
the Human Rights Council and at the General Assembly in 2010) are a
product of former Advisory Committee member Dr. Shigeki Sakamoto, with
whom we have also collaborated closely.

1. What mechanism has the Government (Federal or State level) put in place to disseminate the Principles and Guidelines to its citizens? e.g. translation into national and local languages; media; or any other mechanism?

Key points of the Principles and Guidelines have been translated into Japanese and are posted on the Ministry of Foreign Affairs website. A word-for-word translation, checked by a leading expert in international law, is available from a non-governmental organization, the Center for Human Rights Education and Training．

1. Have any policies, action plans or any other measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members? Please provide details on measures taken.
2. A policy of forced isolation was continued in Japan until as recently as 1996, when the 1953 revised Leprosy Prevention Act was repealed. There are 13 national sanatoria in Japan, and some now have museums. The museums were built to eliminate stigma associated with leprosy and restore the honor of the former patients and their families, among other reasons. They serve as important information centers on the leprosy issue in Japan. Below are examples:
3. The National Hansen’s Disease Museum

Established in 1993 as a private museum, it reopened as a national museum in 2007. The National Hansen’s Disease Museum offers insights into the history of the disease, life in a former leprosarium, medical information, examples of art and literature by those affected by leprosy, and more. The museum is located on the premises of National Sanatorium Tama Zenshoen in Tokyo and receives 25,000 visitors annually. Recently, a “Social Awareness-Raising Section” was established in the museum’s secretariat that offers free classes on Japan’s leprosy issue to schools, non-governmental organizations, local governments and more.

<http://www.hansen-dis.jp/eng/06standing/06standing.html>

1. The Jukanbo Museum

The “Special Hospital Ward,” or *Jukanbo,* was in operation for nine years at Kuryu Rakusen-en leprosarium in Gunma Prefecture from 1938 to 1947. Despite its name, it was a particularly harsh detention center where inmates of leprosaria nationwide who were regarded as “disobedient” were confined. Of 93 who were incarcerated, 23 died. Only the foundations of the original *Jukanbo* remain, but the government has recreated the “special hospital ward” as a museum for awareness-raising purposes. Through detailed documentation and photos, visitors can learn about the past isolation policy and the background of the individuals sent to the *Jukanbo*. They can enter a small, dark cell (with a shallow toilet in the floor) rebuilt to exactly the same dimensions as the original.

<http://sjpm.hansen-dis.jp/>

1. Facts on leprosy are readily available from the website of the Ministry of Health, Labour and Welfare.

<http://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/kenkou/hansen/>

The ministry also distributes a brochure, “The other side of Hansen’s disease” for children. The brochure provides facts on leprosy (e.g. it is completely curable and only mildly infectious), and refers to Japan’s history of forcible isolation that trampled on the human rights of leprosy patients. The brochure poses children the question: What we can do to prevent the same mistake being repeated in the future.

1. What measures have been taken (Federal or State level) to modify, repeal or abolish discriminatory laws, policies or practices, including terminating forced segregation, in order to eliminate discrimination against persons affected by leprosy and their family members? Is freedom to choose where to live ensured for persons affected by leprosy and their family members?

The 1953 revised Leprosy Prevention Law, which included forcible hospitalization of those diagnosed with leprosy, was abolished in 1996, putting an end to 90 years of isolation policy.

In the lawsuit brought against the government by a group of those affected by leprosy, the Kumamoto District Court admitted in 2001 that taking all factors into account, some aspects of the 1953 revised Leprosy Prevention Law that enabled forced isolation had become clearly unconstitutional at least since 1960.

The government accepted the ruling and took various measures, including the promulgation of the Law to Compensate the Former Interned Persons in the Leprosaria (Leprosy Compensation Law) in 2001 .

Furthermore, the Act on Promotion of Resolution of Issues Related to Hansen’s Disease (\*attachment 1) was enforced in 2009 (hereafter “the 2009 Act”). It was enacted to promote the resolution of Hansen’s disease issues by taking measures for the promotion of welfare, restoration of honor and other related issues. It prohibits the involuntary departure and transfer of residents from national Hansen’s disease sanatoria while making government responsible for taking measures which contribute to the smooth social rehabilitation of those who desire to leave the sanatoria.(Please see Article 10 and Article14)

Persons affected by leprosy are guaranteed the right to live where they choose.

It is also worth noting that the government established a Verification Committee Concerning Hansen's Disease Problem and issued a detailed report on the leprosy issue in Japan in 2005. The report is available online in English.

<http://www.mhlw.go.jp/english/policy/health/01/pdf/01.pdf>

Sponsored by the Ministry of Health, Labour and Welfare, meetings are organized.

<http://www.mri.co.jp/project_related/hansen/>

1. Which is the terminology originally used in your native language in respect of persons affected by leprosy? Please also provide, aside from the specific terminology in your native language, a translation of it in English. Are there any popular myths associated with persons affected by leprosy? Please provide a short description.

*Rai-byo nin* is basically equivalent to leper in English.

There used to be a belief that leprosy in this life was a result of wrongdoings in one's previous life.

**6.** Are those affected by leprosy and their family members being consulted with and/or actively participating in the decision-making processes that deal with matters related to them?

The 2009 Act stipulates the participation of those affected by leprosy in issues related to them (Article 6).

The government consults with representatives of those affected by leprosy on measures regarding leprosy issues at *Hansen byo mondai taisaku kyogikai*, Conference on measures for Hansen’s disease issues.

**7**. What measures have been taken at the national level to ensure persons affected by leprosy enjoy fully and equally rights with others regarding the rights of citizenship; obtaining identity documents; the right to vote; the right to stand for elections; the right to serve the public in any capacity or other civil and political rights?

All of the rights listed above are fully guaranteed by the Japanese Constitution.

**8.** What measures have been taken to ensure persons affected by leprosy enjoy equal rights with others with regard to the rights to work and education; establishing a family; access to public places, including hotels, restaurants; and buses, taxis, trains and other forms of public transport; access to cultural and recreational facilities; access to places of worship or any other economic, social and cultural rights?

All of those rights are guaranteed fully by the Japanese Constitution. There was a case brought to court in 2003 where persons affected by leprosy were refused accommodation at a hotel in Kurokawa Onsen (hot spring), Kumamoto Prefecture. The hotel president was indicted by the District Prosecutors Office in violation of the Hotel Business Law and was charged a penalty. The hotel later went out of business.

**9**. What actions have been taken to promote and protect the human rights of (a) women; (b) children; (c) the elderly; (d) members of other vulnerable groups who have or have had leprosy, as well as their family members? Please provide details.

The most notable move was the introduction of the 2009 Act. Its full implementation will cover human rights protection of those affected by leprosy, including the groups listed above.

**10**. What actions have been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons?

Since the disease has basically been eradicated from Japan, so too have discriminatory labelling and offensive language disappeared from daily life. However, Article 3-3 of the 2009 Act certainly covers language. It states that no person shall act in a manner that discriminates against or infringes on any right or interest of, persons affected by leprosy.

**11**. Have Governments drafted and/or adopted a national action plan to implement the Principles and Guidelines? Please attach a copy. Has a national committee been established? Please provide some details as to its mandate, size and composition of members.

The government has not made a “national action plan” to implement the Principles and Guidelines; the principles and guidelines would be implemented with full implementation of the 2009 Act. Articles 4 and 5 make it responsible for national and local governments to formulate and implement measures for, intra alia, promoting the welfare of persons affected by leprosy. The government formed a committee on promotion of the measures related to Leprosy issues

The Ministry of Health, Labour and Welfare meets with those that cover leprosy issues at the prefectural government level at the *Hansen byo mondai taisaku sokushin kaig*i, Conference on promoting measures on leprosy issues.

**12.** What major obstacles, if any, have Governments faced in implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members?

With the abolition of the 1953 revised Leprosy Prevention Law, Japan no longer has any legal obstacles to eliminating discrimination. Past religious beliefs—that the disease is a proof of wrongdoings in a previous life, for example—no longer exist today. However, since the disease is basically eradicated in Japan (with only a few new cases among immigrant workers detected annually), the biggest obstacle probably is the fact that many people do not know about the disease any more. This makes leprosy issues distant, which makes awareness-raising more difficult.

**13.**  In your view, what follow-up mechanisms should be put in place at the national and international levels to effectively implement the Principles and Guidelines?

Please refer to the attached report (\*attachment 2) by the International Working Group sponsored and supported by the Nippon Foundation.

In order to raise awareness of issues related to leprosy—a disease that is disappearing from around the world—we also believe it important to preserve the memories, as well as facilities that were built to isolate those affected by leprosy and their families in various countries.

**14**. Are there any concrete measures taken by Governments at different levels that you can share with us regarding actions taken to eliminate discrimination against leprosy affected persons and their family members in your country?

The most important measure taken nationally is enactment of the 2009 Act. National and local governments are expected to take measures called for by this act.

There are museums run the government (referred to in Q3) that focus on leprosy issues.

The government holds a symposium on leprosy issues. (See below but in Japanese.)

<http://www.moj.go.jp/JINKEN/jinken80.html>

<http://www.mhlw.go.jp/topics/2012/02/dl/120214-01_09_09.pdf>

The Ministry of Health, Labour and Welfare designates June 22, the date when the Compensation Act came in effect, as the day to commemorate and restore the honour of those affected by leprosy. It has held a ceremony on that day since 2009.

**15**. Please provide identified cases of discrimination experienced by leprosy affected persons and their family members in your country, disaggregated by its different forms, including de facto discrimination.

As discussed in Q3, there was a case in which a group of those affected by leprosy were refused accommodation at a hotel in Kurokawa Onsen (hot spring), Kumamoto Prefecture. The incident was highly publicized in newspapers and other media. The National Sanatorium Kikuchi Keifuen in Kumamoto received calls and letters of encouragement, but it also received hate mail.

**Deadline for submission of responses:**

All parties are encouraged to submit their responses via email or fax as soon as possible but no later than **30 October 2015** to:

**hrcadvisorycommittee@ohchr.org**[Subject: HRCAC Elimination of discrimination against persons affected by leprosy]

or

Secretariat of the Human Rights Council Advisory Committee

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Thank you in advance for your contribution.

For more information about the Advisory Committee, please visit <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/HRCACIndex.aspx>

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1. A/HRC/AC/15/L.3 [↑](#footnote-ref-1)