**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?

知っている。

日本政府が原則・ガイドラインに則った政策を行うよう注目をしている。

Yes. We closely watch the Government of Japan to see that it formulates policies according to the Principles and Guidelines.

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?

日本政府に対し、全療協は（1951年結成）ハンセン病問題基本法（2009年4月施行）の完全な実施を求めて要求を行っている。したがって完全な実施がされれば、ほぼガイドラインは実行されていくと思っている。

Founded in 1951, *Zen-Ryo-Kyo*, the National Hansen's Disease Sanatoria Residents' Association, demands full implementation of the Act on Promotion of Resolution of Issues Related to Hansen’s Disease, which came into force in April 2009 (hereafter “the 2009 Act”). We believe full implementation of the Act will lead to implementation of the guidelines.

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.

基本法によって国及び地方公共団体は差別のない社会を実現するための施策を策定、実施する責任を負っている。したがって国、地方自治体も出来るだけ多く啓発活動を行うよう努力していると思う。

The 2009 Act makes the central and local governments responsible for making and implementing measures to realize a society free from discrimination. We believe governments at both the national and local level are making efforts to conduct as much awareness-raising activities as possible.

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?

1996年3月31日、隔離法である「らい予防法」廃止。どこに住むのかも自由。

The Leprosy Prevention Law, which enforced the isolation of patients, was abolished on March 31, 1996. Persons affected by leprosy have freedom to choose where to live.

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.

ライ病。「かったい」という方言もある。

宗教（仏教）＝因果応報思想（前世で何か悪いことをしたからバチがあたった）信仰心ないため罰として。

俗説＝家筋（血脈）の病気であるとみなされ、家全体の恥とされた。

“*Rai-byo*” is basically equivalent to “leper.”

Local terms, or dialect, also exist, such as “*Kattai*.”

In Buddhism, there is a concept of “retributive justice” -- a disease in this life is punishment for the wrongdoings in one's previous life; there is also a belief that disease is punishment for a lack of religious devotion.

It is also widely believed that the disease is in the family line (the blood line) and brings shame on the whole family

1. 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?

ハンセン病問題対策協議会（座長・厚労省副大臣）2001年設置、第1回開催（6月22日・追悼の日）。政策の助言、提言を行っている。政策の改善も要求。

*The* Conference on measures for Hansen’s disease issues, *Hansen byo mondai taisaku kyogikai,* was established in 2001 headed by the Vice Minister of Health, Labour and Welfare. The first conference was held on June 22, the day designated to commemorate those affected by leprosy. We give advice and suggestions on matters that relate to us. We also demand an improvement in current policies.

1. 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?

日本国憲法により選挙法が改正され、患者にも選挙権が認められる。職業選択の自由、移動の自由などの自由権が予防法によって制限。制限された人権の回復のため患者団体（全療協）を結成し国と闘った。

The election law was amended based on the Japanese Constitution, and leprosy patients obtained the right to vote. Freedom to choose one's occupation and freedom of movement, among others, were restricted by the Leprosy Prevention Law. Patients formed themselves into a group to regain their human rights. The group became what is known today as *Zen Ryo Kyo*, the National Hansen’s Disease Sanatoria Residents’ Association.

1. 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?

制限された全ての権利の回復のため全療協は闘ってきた。人間の尊厳を回復するために闘ってきたといえる。

We have fought to regain all of the rights that had been restricted. It can be said that our fight was to regain human dignity.

1. 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.

全療協は人間回復の闘いの中で、他の患者団体（結核、エイズなど）弱い立場の人々との共闘の重要なことを学んだ。

In the fight by *Zen-Ryo-Kyo* to regain human dignity, we have learned the importance of presenting a united front with other vulnerable people, such as patient groups for TB and HIV/AIDS.

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

ハンセン病患者・回復者に対する差別、その他の権利利益を侵害する行為をしてはならないと基本法3条3項で規定

The Article 3-3 of the 2009 Act states that no person shall act in a manner that discriminates against, or that 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.

行動計画までは策定していないと思う。

I do not believe the government has gone as far as drafting a national action plan.

**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?

ハンセン病問題基本法をまず完全実施すること。特に医療サービス＝医師不足解消。

We believe it necessary for the 2009 Act to be fully implemented. In particular, measures need to be taken in the field of medical services, as we have a shortage of doctors.

**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?

全ての問題解決になお一層の努力が必要。

More effort is necessary to solve all the problems.

**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?

ハンセン病患者が社会から排除されてきた構図は同じ。国民へのなお一層の啓発。

Despite a certain amount of efforts made by the government, the basic societal structure which enables the discrimination of those affected by leprosy persists. To this end, more awareness raising is necessary.

**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.

ハンセン病患者・回復者への差別事例

1. 社会と程度の医療の質及び水準が提供されているとはいえない。
2. 回復者が居住場所を探す際の差別

家族に対する差別事例

1. 結婚の場合受ける差別、病気のことを理由とする破談
2. 学校でのいじめ
3. 就職の際、過度な身の上調査、差別につながる。

Examples of discrimination against those affected by leprosy

1. The quality and standard of medical services provided is not the same as for the rest of society
2. Difficulties encountered when looking for somewhere to live

Examples of discrimination against family members

1. Some marriages break because of the disease
2. Bullying at school
3. Excessive background checks for employment, resulting in discrimination

Please note that we have included past experiences/occurrences in answering this question.

**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**](mailto: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)