Pontifical Council for Health Care Workers The Good Samaritan Foundation The Nippon Foundation

INTERNATIONAL SYMPOSIUM

Towards Holistic Care for People with Hansen's Disease, Respectful of Their Dignity

Vatican City 9-10 June 2016

Auditorium "P. Agostino Trape" Patristic Institute Augustinianum

In cooperation with Fondation Raoul Follereau Sovereign Order of Malta Sasakawa Memorial Health Foundation

Presentation

Leprosy, also known as Hansen's disease, is an infectious disease caused by the bacillus *Mycobacterium leprae*. It is one of the oldest diseases known to humankind and has been feared through the centuries for its disfiguring effects. Today, thanks to modern chemotherapy, there is an effective cure. With early diagnosis and prompt treatment, the disability associated with leprosy can be prevented.

Since the introduction of multidrug therapy (MDT) in the 1980s, an estimated 16 million people have been cured of the disease and leprosy has been eliminated as a public health problem in almost every country. Today, around 200,000 new cases of leprosy are reported worldwide each year.

According to the WHO's most recent Global Leprosy Update, 94% of all new cases in 2014 were attributed to 13 countries: India, Indonesia and Brazil each reported more than 10,000 cases, while DR Congo, Ethiopia, Madagascar, Nigeria, Tanzania, Bangladesh, Myanmar, Nepal, Sri Lanka and the Philippines each reported between 1,000 and 10,000 cases.

Although annual case numbers have declined compared to the past, leprosy continues to pose many problems. Patients diagnosed late may already be suffering from severe nerve damage and irreversible disabilities that require lifelong care. New cases in children continue to be detected, a clear indication that transmission is ongoing. In addition, there are hidden, localized hotspots of leprosy transmission, often in hard-to-reach areas, even in countries that have already achieved the status of 'elimination as a public health problem', which the WHO defines as a prevalence rate of leprosy of less than 1 case per 10,000 people.

In order to further reduce the disease burden, concerted efforts are being made by WHO, governments of endemic countries, Church institutions and other faith communities, international NGOs and associations of people affected by leprosy, but still more work needs to be done.

Leprosy has another aspect that imposes a heavy burden on those it affects. Many myths and misperceptions about leprosy persist. While drugs can cure the disease, they cannot erase the social stigma and prejudice that come from a lack of public understanding. Discrimination against people affected by leprosy remains severe in some parts of the world. Denied the same opportunities for education, employment and marriage as other members of society, people affected by the disease find themselves marginalized and hard-pressed to support themselves. Their access to social services is in some instances limited or non-existent and their perfectly healthy children may be refused admission to school. At stake here are the rights and dignity of people affected by leprosy and their families, as well as their access to much needed care and support.

The plight of the affected brothers and sisters calls for concrete solidarity and authentic fraternity in line with what – during this Jubilee Year of Mercy – we are taught by Pope Francis, who exhorts us to imitate Christ, and therefore "before the poor or the sick, we should not be afraid to look the afflicted person in the eye, and be close to the suffering person with tenderness and compassion" (*Angelus* 15 February 2015).

Embracing this call and wishing to enhance the commitment to caring for people with leprosy and supporting those who have been cured of it, and in order to increase the sensitivity of men and women of goodwill, the Pontifical Council for Health Care Workers through its The Good Samaritan Foundation and The Nippon Foundation have organized a two-day International Symposium around the theme 'Towards Holistic Care for People with Hansen's Disease, Respectful of Their Dignity' which will take place on Thursday and Friday 9-10 June 2016 in Rome at the 'P. Agostino Trape' auditorium of the 'Augustinianum' Patristic Institute in Via Paolo VI, n. 25.

The meeting which is organized with the collaboration of the Raoul Follereau Foundation, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation, will be attended by some two hundred participants, composed of representatives from Ministries of Health, non-governmental organizations working in leprosy, people affected by leprosy and their associations, Church institutions, religious leaders, academic researchers and the media.

Among others, the two-day meeting wishes to: build awareness of general public about leprosy and its medical, mental and social consequences; learn from people affected by leprosy and their family members about their experiences; share new initiatives towards the elimination of the disease, stigma and discrimination against people affected by leprosy; underscore the role that the Catholic Church and other faith communities already play in tackling leprosy and discrimination, and how this might be further enhanced; bring together faith leaders from different religions and seek support in disseminating correct information about leprosy and a message of tolerance and inclusion.

This international meeting will be composed of six sessions. The first session will deal with the current state of the global fight against leprosy as a medical issue. The second session will discuss the human rights aspect of leprosy, inviting experts from the UN Human Rights Council Advisory Committee and other human rights organizations to speak. The third session will look at the role of the Church and other faith-based organizations in tackling leprosy and include an inter-faith dialogue between religious leaders on the role of religion in enhancing awareness of the disease and dispelling discrimination. The fourth session will present some good practices. The fifth session will feature first-person accounts from people affected by leprosy and their associations. Then the sixth and final session will entail a presentation of some project proposals in favor of people with leprosy.

Conclusions and recommendations will be proposed at the end of the symposium by the participants.

It is our sincere hope that the meeting will enhance awareness about the plight of our brothers and sisters affected by leprosy, foster sharing of experience in order to learn from each other about best practices in care and support, as well as spur commitment to the elimination of leprosy and the social stigma and discrimination of those affected by the disease.

> **★ Zygmunt Zimowski** President of the Pontifical Council for Health Care Workers (Holy See)

H. E. Yohei Sasakawa Chairman of The Nippon Foundation (Japan) World Health Organization Goodwill Ambassador for Leprosy Elimination Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy

INTERNATIONAL SYMPOSIUM

Towards Holistic Care for People with Hansen's Disease, Respectful of Their Dignity

A TRIPLE CHALLENGE Reducing the Disease Burden Helping the Sick and their Families

Integrating them into Society

Vatican City • 9-10 June 2016

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THURSDAY 9 JUNE

- 8.50 FILM Leprosy in Our Time
- 9.00 Introduction

H.E. Msgr. Zygmunt Zimowski President of the Pontifical Council for Health Care Workers (Holy See)

Mr. Yohei Sasakawa

Chairman of The Nippon Foundation (Japan) World Health Organization Goodwill Ambassador for Leprosy Elimination; Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy 9.30 Greetings - Hon. Beatrice Lorenzin Minister for Health (Italy) - H.E. Dominique Prince de La Rochefoucauld-Montbel Grand Hospitaller of the Sovereign Order of Malta - H.E. Mr. Armindo F. Do Espirito Santo Vieira Ambassador of the Republic of Angola to the Holy See Dean of the Diplomatic Corps accredited to the Holy See - Mr. Michel Récipon President of the Fondation Raoul Follereau (France) - Mr. Vaqavathali Narsappa President, Association of People Affected by Leprosy (India) Prolusion 10.00 'Care for People with Leprosy: a History of Mercy and Holiness' His Eminence Cardinal Robert Sarah Prefect of the Congregation for Divine Worship and the Discipline of the Sacraments (Holy See) 10.30 Break Hansen's Disease: Epidemiological Data and Future Scenarios 10.45 Dr. Erwin Cooreman Team Leader, Global Leprosy Programme, World Health Organization (New Delhi/India)

MEDICAL-SCIENTIFIC ASPECTS: PREVENTION-TREATMENT-ASSISTANCE-RESEARCH

Chairman: Dr. Christian Johnson Medical Adviser, Fondation Raoul Follereau (France)

11.15 The Fight against Leprosy: Current Challenges and Strategies Dr. Marcos Virmond President, International Leprosy Association (Brazil)

- 11.30 The Elimination of Leprosy and Neglected Diseases as a Problem of Public Health Dr. Francesco Maraglino Head of the Office for Infectious Diseases at the Directorate for Health Prevention, Ministry of Health (Italy)
- 11.45 **Prevention and Treatment Prof. Stewart Cole** President of the Medical Commission, Fondation Raoul Follereau (Switzerland)
- 12.00 Assistance and Research Dr. Ann Aerts CEO, Novartis Foundation (Belgium)
- 12.15 Debate
- 13.00 Lunch

ASPECTS OF HUMAN RIGHTS

Moderator: H.E. Msgr. Bernardo Johannes Bahlmann, OFM Bishop of Óbidos (Brazil)

- 15.00 Dignity and the Right to Protection of Health of People with Leprosy Prof. Barbara Frey Director of Human Rights Program, University of Minnesota and Member of the International Working Group of Leprosy and the Humans Rights Project (USA)
- 15.20 Legal Instruments for the Recognition of the Dignity of People with Leprosy and their Social Integration *Dr. Obiora Okafor Chairperson, United Nations Human Rights Council Advisory Committee (Nigeria)*
- 15.40 **Social Stigma and Prejudice** *Mr. Tatsuya Tanami Executive Director, The Nippon Foundation (Japan)*

- 15.55 **Stigma and Toxic Imagery** *Mr. José Ramirez, Jr International Association for Integration, Dignity and Economic Advancement – IDEA (USA)*
- 16.10 Break
- 16:40 Access to Education, Work and Marriage *Prof. Yozo Yokota President, Center for Human Rights Education and Training (Japan)*
- 17:00 Discussion
- 18.00 Concert
- 18:30 End of the Deliberations
- 19.30 Buffet Dinner Reception

FRIDAY 10 JUNE

THE CONTRIBUTION OF THE CHURCH AND OTHER FAITH COMMUNITIES

9.00 **ROUND TABLE**

Moderator:

Dr. Mary Healey Sedutto Founder and Director of the'Hope for a Healthier Humanity' Foundation (USA)

- The Catholic Church

The Results of the Survey Carried out by the 'Good Samaritan' Foundation on the Activities and Projects of the Catholic Church Connected with Care for People with Leprosy

- Judaism Prof. Riccardo Di Segni Chief Rabbi of the Jewish Community of Rome - Islam Mr. Abdel Latif Chalikandi Advisor to Tawasul Europe Centre for Dialogue, Rome Representative, Maqasid Institute, London (United Kingdom)

- Hinduism

Dr. P.K. Gopal President, Integration, Dignity & Economic Advancement of people affected by leprosy - IDEA India (India)

- Buddhism

Dr. Phramaha Boonchuay Doojai Buddhist monk, Chairperson of the Asian Interfaith Network on AIDS (AINA), and Dor of Thailand's Chiang Mai Buddhist College (Thailand)

10.15 Discussion

10.30 Pausa

GOOD PRACTICES AND TESTIMONIES

Moderator: Dr. Annick Chauty Fondation Raoul Follereau (Benin)

- 11.00 The Concern and Care of the Church in India for People with Leprosy *Rev. Dr. Arputham Arulsamy Associate Director of Catholic Health Association of India (India)*
- 11.20 The Social, Political and Health-care Role of Civil Society in Indonesia *Ms. Vivian Velema-Andyka Country Director, Netherland Leprosy Relief – NLF (Indonesia)*
- 11.40 The Pastoral Project for People with Leprosy in the Diocese of Bunia (D.R. Congo) *Sr. Jeanne Cécile Physician, Coordinator, Diocesan Offices for Medical Work -BDOM), Bunia (R.D. Congo)*

TESTIMONIES OF ASSOCIATIONS, NGOS AND ORGANISATIONS OF PEOPLE AFFECTED BY LEPROSY

Moderator:

Prof. Takahiro Nanri Program Director, Special Project Coordination Team, The Nippon Foundation, and Associate Professor, Atomi University (Japan)

12.00 Testimonies

Ms. Seminiana Bawik Coalition of Leprosy Advocates of the Philippines

Rev. Fr. Giorgio Abram, ofm Conv Priest, doctor and missionary (Italy)

Mr. Miyoji Morimoto President, IDEA (Japan)

- 13.00 Lunch
- 14:30 Mr. Kofi Nyarko (Ghana)
 - Comments: Mr. Kang Seonbong (Korea) Mr. Du Chaoming (PR China)
- 15:10 Mr. Francisco Onde (Philippines)
 - Comments: Mr. Hibisitu Chaneyalew Getahune (Ethiopia) Ms. Maria Eloisa Castro (Colombia)
- 15:50 Ms. Valdenora da Cruz Rodriguez (Brazil)
 - Comments: Mr. Paulus Manek (Indonesia) Ms. Maya Renavare (India)
- 16.30 Coffee Break

PROPOSAL OF PROJECTS IN FAVOUR OF PEOPLE WITH LEPROSY

Moderator: *Mr. Harald Schmidt de Gruneck Former Director of the Sovereign Order of Malta programs in Cambodia (Switzerland)*

- 17.00 **Presentation of Projects**
 - Project in Mali AIFO Benin
 - A Research Project Asia
 - Project for Integration Brazil
- 17.45 **Conclusions and Recommendations Rev. Fr. Michele Aramini** Professor of Theology at the Sacred Heart Catholic University of Milan (Italy)
- 18.30 End of the Symposium

EXECUTIVE COMMITTEE

Mgr. Jean-Marie Mupendawatu

Mgr. Jacques Suaudeau Dr. Takahiro Nanri Dr. Kiyomi Takahashi Dr. Tanami Tatsuya Dr. Ivo Graziani Dr. Christian Johnson Dr. Raniero Guerra Rev. Prof. Michele Aramini

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Information

Conference Secretariat

Pontifical Council for Health Care Workers Via della Conciliazione, 3 – 00193 Rome, Italy Telephone: (06) 69883138 Fax: (06) 69883139 E-mail: opersanit@hlthwork.va

Beginning from June 9th, 2016, the Secretariat will move to the Auditorium "P. Agostino Trape" of the Patristic Institute *Augustinianum* – via Paolo VI, 25 – Roma.

The inscription to the Congress is free

All those who wish to participate in the International Conference must send in the completed registration form to the Pontifical Council for Health Care Workers, 00120 Vatican City, not later than June 5, 2016.

There will be simultaneous translation into English, French, and Italian.

For admission to the Auditorium, participants will have to present an ID badge, which can be collected from the Office of the Pontifical Council from **Monday, June 6 to Wednesday, June 8** (from 9.00 a.m. to 6.00 pm.), then on Thursday, June 9 the Secretariat will be transferred to the Auditorium "P. Agostino Trape" of the Patristic Institute *Augustinianum*.

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Registration Form

Surname	
First Name	
Profession	
Address	Zip Code
City	State
Telephone	Fax
E-mail	

In accordance with ACT No. 196/2003 on personal data protection, the declarant grants his consent to the processing of his personal data for the purpose and to the extent necessary for the management of information and communications related to the organization of the Conference.