

# International Symposium at the Vatican on Hansen's Disease "Leave No One Behind"

# GLOBAL APPEAL 2023

to End Stigma and Discrimination against Persons Affected by Leprosy

January 23-24, 2023

Auditorium "P.Agostino Trape" Patristic Institute Augustinianum

Dicastery for Promoting Integral Human Development
French Raoul Follereau Fondation
Italian Association Amici di Raoul Follereau
Sasakawa Leprosy (Hansen's Disease) Initiative

# About Hansen's Disease

Leprosy, also known as Hansen's disease, is an infectious disease that mainly affects the skin and peripheral nerves. Prior to the COVID-19 pandemic, over 200,000 new cases were being reported annually. Leprosy is curable with multidrug therapy, but left untreated can result in permanent disability. An estimated 3 to 4 million people are thought to be living with some form of disability as a result of leprosy. Myths and misunderstandings about the disease persist. In various parts of the world, patients, those who have been treated and cured, and even their family members continue to be stigmatized. The discrimination they face limits their opportunities for education, employment and full participation in society.

# About International Symposium at the Vatican on Hansen's Disease

In 2016, an International Symposium was held at the Vatican titled "Towards Holistic Care for People with Hansen's Disease, Respectful of their Dignity." Held at the same venue as the current symposium, it was organized by The Pontifical Council for Health Care Workers, The Nippon Foundation and the Good Samaritan Foundation in cooperation with French Raoul Follereau Fondation, the Sovereign Order of Malta and Sasakawa Health Foundation. Around 200 people from some 45 countries took part in the two-day meeting, among them persons affected by leprosy, human rights experts, WHO officials, NGO representatives, as well as representatives of the Catholic Church and other major faiths.

They heard speakers address medical and scientific aspects of leprosy, human rights issues, the contribution of the Catholic Church and other faith communities, examples of good practices and projects, as well as powerful testimonies from people affected by leprosy about the impact of the disease—and society's response to it—on their lives. Conclusions and Recommendations\* were presented at the end of the symposium and were approved in principle by the organizers and participants.

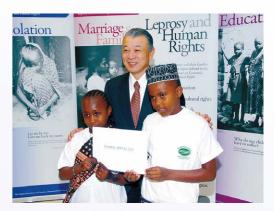
Since that symposium, new case numbers remained more or less constant up until the coronavirus pandemic, which disrupted leprosy services and led to a large drop in new cases from 2020. The pandemic also made it harder for persons affected by leprosy to receive treatment and disability care, and impacted their day-to-day lives and the lives of many other socially vulnerable individuals. Against this backdrop, the Dicastery for Promoting Integral Human Development and Sasakawa Leprosy (Hansen's Disease) Initiative as well as French Raoul Follereau Fondation and Italian Association Amici di Raoul Follereau, have agreed to co-host a second international symposium on Hansen's Disease. At this symposium, we aim to examine the progress made against leprosy over the past six and a half years and the challenges that remain, and provide stakeholders with an opportunity to discuss future actions to realize a world free from leprosy and its associated problems. More broadly, the symposium will also consider how socially vulnerable individuals and communities,

especially those consisting of persons with disabilities due to disease, have been affected by the coronavirus pandemic, and propose ways we can work toward a society in which no one is left behind. In addition, the symposium will incorporate the launch ceremony for Global Appeal 2023 to End Stigma and Discrimination against Persons Affected by Leprosy.

# About Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy

Initiated in 2006 by Yohei Sasakawa, the WHO Goodwill Ambassador for Leprosy Elimination and Chairman of The Nippon Foundation, the Global Appeal is an annual message to spread awareness and call for an end to the discrimination that persons affected by leprosy continue to face. The appeal is issued every January on or near World Leprosy Day and receives the support of influential partners from different fields to build solidarity and ensure that its message reaches far and wide.

Global Appeal 2023, the 18th in the series, will be launched from the Vatican during the International Symposium on Hansen's Disease, endorsed by the organizers and participants of the symposium, who represent stakeholders from all over the world working for a world without leprosy.



Global Appeal 2008: Launched in London, it was endorsed by internationally recognized organizations with a focus on human dignity and human rights.

Year	Signatories	Location
2022	World's philanthropic organizations	Online
2021	International Trade Union Confederation	Online
2020	International Paralympic Committee	Tokyo, Japan
2019	International Chamber of Commerce (ICC)	New Delhi, India
2018	Disabled Peoples' International	New Delhi, India
2017	Inter-Parliamentary Union	New Delhi, India
2016	Junior Chamber International	Tokyo, Japan
2015	International Council of Nurses	Tokyo, Japan
2014	National human rights organizations	Jakarta, Indonesia
2013	Members of the International Bar Association	London, UK
2012	Members of the World Medical Association	Sao Paulo, Brazil
2011	World's leading universities	Beijing, China
2010	World's business leaders	Mumbai, India
2009	World's religious leaders	London, UK
2008	International human rights organizations	London, UK
2007	Representatives of people affected by leprosy around the world	Manila, Philippines
2006	World leaders and Nobel Peace Prize laureates	New Delhi, India

<sup>\*</sup>See highlights of the Conclusions and Recommendations on the back cover of this pamphlet and the entire document at https://www.nippon-foundation.or.jp/media/archives/2018/en/news/articles/2016/img/32/7.pdf

# Dicastery for Promoting Integral Human Development



The Dicastery for Promoting Integral Human Development was created on August 17, 2016 according to the wishes of Holy Father Pope Francis. The Dicastery promotes the integral development of the person in light of the Gospel and in line with the

Social Doctrine of the Church. It dedicates particular attention to taking care of the goods of justice, peace and the safeguarding of Creation, as well as issues regarding disarmament, human rights, human mobility, health, charitable works, expressing the concern and attention of the Pope towards a humanity that suffers, among whom are the needy, the ill and the excluded. In addition, the Dicastery follows issues regarding the necessities of those who are forced to abandon their own countries or those who are without one, the marginalized, the victims of armed conflicts and natural disasters, prisoners, the unemployed and victims of contemporary forms of slavery and torture and other people whose dignity is at risk. The Dicastery promotes its activities by means of a network of interactions that involve local Churches, Episcopal Conferences, the other organs of the Roman Curia, the international organizations (both Catholic and non-Catholic), the relations with governments and supranational organizations.

# French Raoul Follereau Fondation



Following the Association of Raoul-Follereau Foundations created in April 1968, the French Raoul Follereau Fondation was recognized as a public utility in 1984 and it continues the fight of its founder: "to build a world without leprosy",

by implementing his message of charity. By placing man, without distinction of origin or religion, at the heart of its projects and by favoring in-depth actions aimed at treating, educating and reintegrating, the Foundation fights against all forms of exclusion caused by illness, ignorance or poverty. It works to mobilize a true community of generosity that brings together donors, partners and volunteers for a fairer and more humane world. "To live is to help others to live!" This is the motto Raoul Follereau proclaimed in 1918 and which would animate his whole life. Follereau and his wife, Madeleine, devoted their lives to a fight—a fight to improve the situation of people affected by leprosy and to alleviate world suffering. Follereau himself traveled around the world 32 times in order to adapt aid to real needs. He created World Leprosy Day in 1954.

# Italian Association Amici di Raoul Follereau (AIFO)



AIFO is a Non-Governmental Organisation that promotes international cooperation initiatives and works with communities in the most disadvantaged areas. Since more than 60 years, AIFO aims to spread and make concrete Raoul Follereau's dream, 'the Civilisation of Love' with particular attention towards the persons affected by leprosy and disabilities: addressing health, social and economic problems and through integrated and sustainable development projects, AIFO works in 11 countries in Africa, Asia and South America, in collaboration with local

NGOs, religious congregations, grass-root organisations and governmental authorities. In Italy, AIFO is based in Bologna and thanks to its 38 local groups of volunteers, it advocates for inclusion for everyone: no one excluded! The association promotes education for a better understanding of causes underlying worldwide poverty.

In all the countries where it works, AIFO is committed to the implementation of the UN Convention on Rights of Persons with Disabilities (CRPD) and it has adopted the Community-Based Inclusive Development (CBID) approach. AIFO is a founding member of ILEP (International Federation of Anti-Leprosy Associations), of IDDC (International Disability & Development Consortium) and is in official relationship with the World Health Organisation (WHO).

# Sasakawa Leprosy (Hansen's Disease) Initiative







Sasakawa Leprosy (Hansen's Disease) Initiative is a strategic alliance that links together the WHO Goodwill Ambassador for Leprosy Elimination, Sasakawa Health Foundation, and The Nippon Foundation for the purpose of achieving a leprosy-free world. The current World Health Organization (WHO) Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa, has visited over 90 countries in this role to learn about and raise awareness of the challenges associated with the disease since his appointment in 2001. He has gained a global perspective and he

is in a unique position to advocate for persons affected by leprosy and their families. Sasakawa Health Foundation (SHF) was co-founded in 1974 by Yohei's father, Ryoichi Sasakawa, and Morizo Ishidate, a pharmacologist who was the first person to synthesize a drug treatment for leprosy in Japan. SHF is committed to a public health approach and collaborates with a wide range of stakeholders in order to address interrelated medical and social issues. The Nippon Foundation (TNF), also founded by Ryoichi Sasakawa, has been providing generous funding to leprosy-related initiatives since 1967. Yohei Sasakawa is the current chairman of TNF.

+ DAY2: Tuesday, January 24, 2023		
9:00 - 9:05	Prayers	
+	− Theme: Toward Realizing a Society in Which No One Is Left Behind —+	
9:05 - 9:20	Keynote Speech: What has been the impact of the COVID-19 pandemic on the socially vulnerable, especially on those who are with disabilities?	
	Dr. P. Narasimha Rao, President of the International Leprosy Association and Indian Association of Leprologists	
9:20 - 10:45	Testimony Moderator: Mr. Amar Timalsina, Executive Director of IDEA Nepal Ms. Dimby and Ms. Soavina, Persons affected by Hansen's disease, Madagascar (video) Mr. Rajni Kant Singh, State Coordinator for Bihar Operations, LEPRA Society, India (video) Ms. Paule Helena Biaka, A person affected by buruli ulcer, Cote d'ivoire (video) Mr. Juan Alberto López Padilla, A person affected by leishmaniasis, Colombia Mr. Sarang Gayadhane, Secretary of Association of People Affected by Leprosy (APAL), India Ms. Patrícia Gonçalves Soares, Coordinator of the Department of Policies for Women, Morhan, Brazil	
10:45 - 11:15	Coffee break	
11:15 - 12:45	Best Practices with special attention to the roles of religious organizations  Moderator: Mr. Patrice Simonnet, Director General of AIFO  Speakers: Mr. Thierry zen Ruffinen, President of Fondation CIOMAL de l'Ordre de Malte  Sr. Sabine Ramasinoro, Head of Marana Centre, Madagascar  Dr. Jose Manikkathan, Director of AIFO India  Sr. Bawani Chelliah, Order of Franciscan Missionaries of Mary, Sri Lanka  Sr. Gladis Estela Llano Uribe, Director of Villa Bernarda Foundation, Colombia  Q&A session	
12:45 - 14:15	Lunch	
+	Recommendations and suggestions on how to move forward from the conclusions and recommendations adopted in 2016  Moderator: Msgr. Robert J. Vitillo, Secretary General of International Catholic Migration Commission	
14:15 - 15:25	Session 1: Perspectives of key actors from the Global Leprosy Community  Dr. Vivek Lal, Team Leader of Global Leprosy Programme, WHO  Dr. Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members (video)  Dr. Margarida Cristiana Napoleão Rocha, Technologist at the Ministry of Health, Brazil  Dr. Benedict Quao, Programme Manager of the National Leprosy Control Programme, Ghana  Mr. Geoff Warne, CEO of ILEP  Mr. Bill Simmons, CEO of American Leprosy Missions and Chair of Global Partnership for Zero Leprosy (GPZ)	

Dr. P. Narasimha Rao, President of the International Leprosy Association and Indian Association of Leprologists

Ms. Arielle Cavaliero, Global Business Director of Leprosy Global Health Program at Novartis

Ms. Letícia Cezar da Frota, Miss World Brazil 2022

Ms. Maya Ranavare, President of Association of People Affected by Leprosy (APAL), India and the representative of the 2nd Global Forum of People's Organizations on Hansen's Disease Q&A session

### 15:25 - 15:55 Coffee break

### Session 2: Perspectives of the Organizers 15:55 - 16:45

Mr. Patrice Simonnet, Director General of AIFO

Dr. Roch Christian Johnson, Medical Director of French Raoul Follereau Fondation

Dr. Takahiro Nanri, Executive Director of Sasakawa Health Foundation/Sasakawa Leprosy Initiative

A representative of Dicastery for Promoting Integral Human Development, Holy See Q&A session

16:45 - 16:55 Wrap-up & Closing Remarks

### Panel Discussions Wrap-up 17:10 - 17:15

# Excerpts of Conclusions and Recommendations from the first symposium

# CONCLUSIONS

- 1. Every new case of Hansen's disease is one case too many.
- 2. Every case of stigma and social exclusion is one case too many.
- 3. Every law that discriminates against persons affected by Hansen's disease is one law too many.

# RECOMMENDATIONS

# Two Introductory Points

- 1. Persons affected by Hansen's disease must be seen as the main actors in the fight against this disease and the discrimination it causes. This involvement is a powerful instrument for the recognition of their equal dignity and rights for social inclusion, and for the breaking of the stigma attached to them. This point applies to all of the recommendations listed below.
- 2. The use of discriminatory language that reinforces stigma must cease, in particular, use of the term 'leper' and its equivalent in other languages. This term is offensive for the reasons stated above and also because it defines a person by his or her illness. Use of the term "leprosy" in a metaphorical sense should be avoided.

## Five Recommendations

- 1. Given their important role in their respective communities of believers, the leaders of all religions and this is an important and urgent matter should, in their teachings, writings and speeches, contribute to the elimination of discrimination against persons affected by leprosy by spreading awareness that leprosy is curable and stressing that there is no reason to discriminate against anyone affected by leprosy or members of their families.
- 2. States and governments should be encouraged to make great efforts to implement the 'Principles and Guidelines' accompanying the resolution adopted by the General Assembly of the United Nations in 2010 on Elimination of discrimination against persons affected by leprosy and their family members. These 'Principles and Guidelines' must be fully implemented, otherwise they will remain just empty proclamations.
- 3. There should be a modification or abolition of all laws and regulations that discriminate against persons affected by leprosy. Policies relating to family, work, schools, or any other area which directly or indirectly discriminate against persons affected by leprosy must also be changed, recognising that no one must be discriminated against because of the fact that he or she has, or once had, leprosy.
- **4.** There is a need for further scientific research to develop new medical tools to prevent and treat leprosy and its complications, and to achieve better diagnostic methods.
- **5.** In order to achieve a world free of leprosy and the discrimination it causes, the efforts of all the Churches, religious communities, international organizations, governments, major foundations, NGOs, and associations of persons affected by leprosy which have hitherto contributed to the fight against this disease should be unified and joint plans of cooperation should be developed.