

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" Patristie Institute Augustinianum



Organizers











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Message by His Holiness Pope Francis

Distinguished Ladies and Gentlemen,

Sisters and brothers!

To all of you a cordial greeting on the occasion of the Second Symposium on Hansen's Disease. I thank you for your commitment to people with this disease who are often forgotten and discarded

Today's symposium is celebrated just days before the 70th World Leprosy Day, initiated by Raul Follereau in 1953 to raise awareness of a disease that many believed to be extinct. What should concern us, now even more than then, is that not only is the disease often forgotten, but also the people who suffer from it.



Leprosy, also known as Hansen's Disease, is one of the oldest diseases in human history, as the Bible testifies. But that which even the Bible is not able to remind us is that the stigma attached to leprosy continues to cause serious human rights violations in various parts of the world to this day.

"Let us admit that, for all the progress we have made, we are still 'illiterate' when it comes to accompanying, caring for and supporting the most frail and vulnerable members of our developed societies. We have become accustomed to looking the other way, passing by, ignoring situations until they affect us directly" (Fratelli Tutti, 64). We cannot forget these brothers and sisters of ours. We must not ignore this disease, which unfortunately still affects so many people, especially in the most fragile social contexts.

On the contrary, convinced of the human family's vocation to fraternity, let us ask ourselves:

"Will we bend down to touch and heal the wounds of others? Will we bend down and help another to get up? This is today's challenge, and we should not be afraid to face it" (ibid., 70).

We must then seize the occasion of World Leprosy Day to review our models of development, and to denounce and seek to correct the discrimination that they cause. This is a favourable occasion to renew our commitment to building an inclusive society that leaves no one on the margins.

Indeed, denunciation must always be accompanied by an alternative, bringing together the good that already exists, even silently, with prophetic visions, capable of inspiring a structured charity and a more just coexistence. In this effort, your contribution — the stimulus and help you give to the local churches — is of great value, so that your local churches may stand alongside those who have been cast aside and know how to actively accompany processes of inclusion and integral human development.

In particular, we must ask ourselves how best to collaborate with people who are affected by leprosy, truly treating them as persons, recognizing them as the main protagonists in their struggle to participate in fundamental human rights and live as full members of the community.

"We must then seize the occasion of World Leprosy Day to review our models of development,"

His Holiness Pope Francis

I hope that this conference will help to unite voices from around the world and to discuss measures that can be taken to further promote respect for human dignity.

I express my closeness to those suffering from Hansen's Disease and encourage them to continue to work to ensure that they do not lack spiritual support and health care. May Christian communities allow themselves to be evangelized by these brothers and sisters and be present at the forefront of efforts for their full integration.

Dear friends, may our Blessed Mother Mary and the many saints and holy men and women who have served Christ in people affected by leprosy sustain you. From my heart I bless you and pray for you — the sick, their families, and those who lovingly care for them. May you all experience that Jesus came so that every man and woman may have life and have it abundantly (cf. Jn. 10:10).

Rome, St. John Lateran, 17 January 2023, Memorial of St. Anthony, Abbot.

His Holiness Pope Francis

Greetings from Organizers



Dr. Pierre-Yves ThiebaultPresident of French Raoul Follereau Fondation

Dr. Pierre-Yves Thiebault recalled the creation of International Leprosy Day, in 1954, by the French humanitarian Raoul Follereau. "At that time, we knew that people were living with Hansen's disease, but we didn't know that there were ten million of them."

"Today we know that 200 thousand new cases are discovered each year in the world, that is, one person every 3 minutes. We know that, among these new cases, one in 10 is a child."

"We must pull our resources together to make this fight more effective", he synthesized.

"We must pull our resources together to make this fight more effective"

Dr. Pierre-Yves Thiebault

Sr. Alessandra Smerilli, F.M.A.

Dicastery for Promoting Integral Human Development, Holy See

The International Symposium at the Vatican started with a greeting from the event organizers. The first one to speak was Sr. Alessandra Smerilli, who recalled the words of Pope Francis: only can we forget the disease, but we can also forget about people.

"Who doesn't turn away?
But who, on the contrary,
stops and kneels? Seeing
the suffering has to inspire
our actions toward those
who are in need. (...) And
that is the very theme of
our symposium, namely,
leave no one behind."



Mr. Antonio LissoniPresident of AIFO

Next, Mr. Antonio Lissoni explained that AIFO manages initiatives to control leprosy in five countries, namely India, Brazil, Mozambique, Guinea Bissau and China.

Mr. Lissoni pointed out that leprosy has taught a lot of things. "We have learned that cooperating means listening to patients. It means growing together with fragile communities. It means working with vulnerable people, not for vulnerable people only."

"People can't be objectified. They can't be only the object."



"We have learned that cooperating means listening to patients."

Mr. Antonio Lissoni

Mr. Yohei Sasakawa Chairman of The Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination

Mr. Yohei Sasakawa emphasized that early detection and treatment of leprosy are of the utmost importance. "Throughout the world, I have met many people who developed disabilities because they were reluctant to go to hospitals due to no initial symptoms, such as pain or fever."

Mr. Sasakawa asked for World Health Organization and medical professionals to continue their effort to actively find new cases.

"I will continue to work with you. Visiting the front lines in support of activities to promote early detection and treatment."



Messages from **Dignitaries**



Mr. Francisco Faustino Pinto National Vice-Coordinator of Morhan, Brazil "Unfortunately, they still haven't learned to see us as a whole. They still see us as pieces: hands, feet, fingers, eyes, nose, nerves and skin. When will our pieces be put together? This is a question I ask myself every day."



H.E. Dr. Michael Mann Ambassador of the Sovereign Military Order of Malta "It is recorded as early as the 13th century that members of the Military Order (of Malta) were instructed that they must provide food and clothing to persons with leprosy."



Mr. Tim Hughes
Deputy Executive Director
of the International
Bar Association

"It is deeply distressing that when the world has the medicine and the cure we still fail to deliver it to some of those who most need it." Mr. Volker Türk United Nations High Commissioner for Human Rights

"Given the physical impairments that are caused by leprosy, **affected people should be fully** recognized as persons with disabilities.

This will encourage states to protect, promote and fulfill the rights of these people and their family members, including by ensuring they can participate in policymaking. "



Dr. Tedros GhebreyesusDirector-General of WHO

"People with leprosy do not define themselves by one disease, and nor should we.

That's why our Global Leprosy Strategy 20 and our Road Map for Neglected Tropical Diseases call for integrating services for leprosy and other diseases with skin manifestations into primary healthcare as part of every country's journey towards universal health coverage."



Launch of the

GLOBAL APPEAL 2023



Full video

This year marks the **150th anniversary** of Dr. G.H. Armauer Hansen's discovery of the bacillus that causes leprosy.

Leprosy, also known as Hansen's disease, is now a curable disease.

With early detection and treatment, disability associated with leprosy can be prevented.

Multidrug therapy, the cure for leprosy, is available free of charge throughout the world. But drugs alone are not enough to overcome social and economic discrimination.

To complete the healing process, we must cultivate the human family's innate vocation to fraternity and recognize that all human beings are brothers and sisters, equal in dignity.

Today, as the **70th World Leprosy Day**, established by Raoul Follereau in 1954, approaches, we stand with persons affected by Hansen's disease.

We join them in working for a world free from the stigma associated with the disease and for an end to social injustice.

Let all of us play our part in realizing an inclusive society in which no one is left behind.

Love your neighbor as yourself (Matthew 22:39)











Tedros Adhanom Ghebreyesus Director-General, WHO



Alice Cruz
United Nations Special Rapporteur on the
Elimination of Discrimination against Persons
Affected by Leprosy and Their Family Members

Day 1 Toward Zero Leprosy

Keynote Speech

Addressing the Current Situation and Remaining Challenges in Leprosy, Six Years after the Adoption of "Conclusions and Recommendations"



Dr. Ibrahima Socé FallDirector of the Department of Control of Neglected Tropical Diseases, WHO

Dr. Fall explained progress in terms of guidance published by the WHO. In 2021, **the launch of WHO Roadmap for Neglected Tropical Diseases 2021–2030** aimed at strengthening the programmatic response to NTDs.

In the same year, the beginning of **the Global Leprosy Strategy 2021–2030** wished to advance progress on the WHO Roadmap and the Sustainable Development Goals.

The UN Special Rapporteur observed she has seen progress in the elimination of interpersonal stigmatization - although it seems to be difficult to eliminate stigma in a context where leprosy is a rare disease.

"I suggest we learn from the organizations of persons affected by Hansen's disease, but also invest more in their development, both as individuals and collectivities."

Dr. Alice Cruz

UN Special Rapporteur on the elimination of discrimination against persons aected by leprosy and their family members



Session 1

Zero Disease & Disability

The first session of the International Symposium at the Vatican addressed the challenges to increase the number of countries with zero new autochthonous cases of leprosy. Speakers work in the medical field, government, international organizations and grassroots organizations from India, Ghana and Colombia. The meeting was moderated by Dr. Vivek Lal, Team Leader of Global Leprosy Programme, World Health Organization (WHO).

To start this first session, Dr. Roch Christian Johnson, Medical Director of French Raoul Follereau Fondation, approached the elimination of leprosy transmission in African countries. Dr. Johnson pointed out that endemicity levels vary among countries. Algeria, Lesotho. Mauritania. Mauritius and São Tomé and Principe have reported no cases for years. On the other hand, the Democratic Republic of the Congo, Ethiopia, Madagascar,

Mozambique, Nigeria and Tanzania have more than a thousand cases annually.

Dr. Johnson emphasized the importance of the WHO Strategic Framework for Integrated Control and Management of Skinrelated Neglected Tropical Diseases 2021-2030 as a tool for supporting national programs, staff training, research and cross-cutting strategies - such as integrated screening.



Afterward, Dr. Paul
Saunderson, Technical
Advisor for American
Leprosy Missions, spoke
about preventing ongoing
leprosy transmission and the
potential of a new vaccine.
Traditionally, prevention has
been case finding and
treatment of cases with
BCG, in infancy, and MDT,
for all cases.

There is a recent development of post-exposure prophylaxis (PEP) with a single dose of Rifampicin that is being gradually constructed.

Future possibilities are a leprosy-specific vaccine, which is currently under trials. "We want to see if it's safe, that is the primary

outcome. Which means it doesn't cause further nerve damage but creates an immune response."

Still within the treatment history, Ms. Arielle Cavaliero, Global Business Director of the Leprosy Global Health Program at Novartis, started her speech. "The introduction of multidrug therapy (MDT), in 1981, had a very impressive impact. It's a fantastic accomplishment within not only leprosy, but in public global public health itself. Over the first decades, we have been seeing a massive decrease in the number of new patients diagnosed per year, something as 95% reduction."

Novartis is now advancing toward leprosy elimination on three interconnected fronts: maintain awareness of leprosy as a global health issue; bring scientific innovations to the field; and continue to develop new ways for all stakeholders to participate efficiently.

"We want to see if (the leprosyspecific vaccine) is safe, that is the primary outcome."

Dr. Paul Saunderson, American Leprosy Missions



Dr. Anil Kumar, Additional Secretary General, Ministry of Health and Family Welfare, India, addressed the topic of eliminating leprosy in his country. Dr. Kumar presented a graph showing that the beginning of awareness campaigns, between 1993 and 1995, triggered an 80% drop in the number of new cases per year, in the country. "We achieved elimination of leprosy in 2005."

Elimination led to a reduction in efforts and a further increase in the number of cases. In 2016, the Ministry of Health launched a new program - this time focused on early case detection. The policy had three fronts: endemic, non-endemic districts and areas of difficult access. As a result, the number of new leprosy cases with Grade 2 Disabilities had a substantial decrease since then.

The current Indian policy, to be released later 2023, aims to accelerate case detection and achieve transmission interruption by 2027, explained Kumar.

Right away, Dr. Benedict Quao, Programme Manager of the National Leprosy Control Programme, Ghana, presented the **Global**



Partnership for Zero
Leprosy Country Model,
implemented in Ghana. The
Country Model approach
strengthens national
programs by helping
governments to analyze
their current activities and
needs, as well as creating
roadmaps that lead
towards zero leprosy.

Dr. Quao also presented the GPZL Country Model cases of Uganda and Nigeria, taking stock of the results of the program in these countries. "The major achievement has been the program's ability to bring partners in-country around a common focus."

Finally, Ms. Lucrecia Vasquez Acevedo, President of Felehansen, Colombia, spoke about the history and challenges of the organization she chairs. Currently, FELEHANSEN is a pool of nine organizations established in nine out of 32 national departments. "And we are proud to say that we work together."

According to Vasquez, organization's work focuses on three areas: advocacy and political incidence; promotion of health prevention and rehabilitation; and social inclusion and economic development.

Session 2

Zero discrimination

The second session tackled the current programs and challenges to eliminate the discrimination and stigma against persons affected by leprosy. The speakers were from England, India, Brazil, Bangladesh, Ethiopia and Indonesia.

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

Mr. Brent Morgan,
International Director of
The Leprosy Mission
International and President
of ILEP, opened the debate.
He pointed out that at the
last Vatican Symposium, in
2016, there were about 150
discriminatory laws, in 23
countries. "Currently, we
believe there are 123 laws in
23 countries that still need
to be repealed or amended.
So there's an overall
reduction of 27."

"Our experience has been that there is no one et lobbying approach; different government departments can be key actors in different jurisdictions."



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countries. There
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reduction of 27."

Mr. Brent Morgan, TLM International Director

Mr. Morgan added that repealing discriminatory legislation is important, but not enough by itself. For that reason, TLM also undertakes three interventions to promote zero discrimination: livelihoods; training for self advocacy; and mobilization of persons affected through self-help groups.

The next speaker was Mr. Gaurab Sen, CEO of Sasakawa-India Leprosy Foundation. The S-ILF approach is to improve life quality through holistic development.

Session 2: Zero discrimination



The S-ILF program consists of four integrated axes: livehood, education, infrasstructure and awareness - and the first two have greater institutional investment.

The educational programs include scholarships for higher education and afterschool learning centers. "The children of persons affected are supported for their higher professional education and skills training, which leads to financial independence."

Mr. Sen also provided a few numbers that illustrate the achieved results. So far, 892 youths have participated in skill development training and 2,845 persons are in livelihood programs.

From **Brazil**, spoke Dr.
Margarida Cristiana
Napoleão Rocha,
Technologist at the
Ministry of Health. Initially,
she provided a brief
historical context of the
issue of discrimination.

According to Dr. Rocha, since 1995 there is a law that prohibits Brazilian government to use the term leprosy and its leads in official documents.

There are also no laws against discrimination.

Despite that, stigma is a reality and discriminatory practices are underreported.

Dr. Rocha also mentioned ministry programs, such as: selfcare groups support, textbooks for schools and online courses. Next, Dr. Tanzina Islam,
Deputy Program Manager
of the National Leprosy
Program, Ministry of Health
and Family Welfare, from
Bangladesh, gave her
report. In 2019, the National
Leprosy Conference was
held in the country, in which
the Prime Minister set the
goal of Global Leprosy
Strategy 2021–2030.

Dr. Islam also mentioned that, in 2011, **Bangladesh** Parliament repealed a British colonial law named the Labour's Act 1898. Therefore, there are no more discriminatory laws in force in the country.

Since 2011, there are no more discriminatory laws in force in Bangladesh.

Nevertheless, a survey conducted in 2017 indicates that social stigma is still a reality.

About 65% of the respondents with deformities stated they think less of themselves; 60% had ever felt ashamed or embarrassed; and 53% had to change their job.

Session 2: Zero discrimination

From then on, the government has started acting on reducing social stigma and discrimination and increasing the rehabilitation for disabled persons due to leprosy.

Mr. Tesfaye Tadesse, Managing Director of Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), spoke from Ethiopia. First of all, Mr. Tadesse brought a brief background about his country. Ethiopia is the second largest population in Africa, where more than 80% of citizens live in rural areas. Currently, Ethiopia lies in second place in Africa and fifth place worldwide in the number of new cases.

"To fight against stigma, we need to strengthen and increase the ability of people who are discriminated against to become agents of change."

Mr. Al Kadri, Chairman of PerMaTa Indonesia ENAPAL was founded in 1996 and currently has 20 thousand members all over Ethiopia. The organization operates in seven areas of the country, which covers approximately 80% of the territorial extension. "Even so, leprosy is still a major issue of discrimination and stigma in Ethiopia."

To face this challenge, Mr. Tadesse enumerated a few recommendations, such as capacity building for organizational development; awareness raising; and economical empowerment of persons affected.

At the end of the session, Mr. Al Kadri, Chairman of PerMaTa **Indonesia**, shared his reflections. Mr. Al Kadri explained discrimination, in Indonesia, is reported by persons affected in many ways, such as inhuman treatment; being seen as underdeveloped and incapable; not being allowed to leave the house; and interaction avoidance due to fear of infection.

"They feel that they are not useful and their needs are not a priority - or are even ignored. (In Indonesia), persons affected often anticipate discrimination."

"We are not a source of the problem but a source of solution for the problems around leprosy.", Mr. Al Kadri stated.



Session 2: Zero discrimination

Day 2 Toward Realizing a Society in Which No One Is Left Behind

Keynote Speech

What has been the impact of the COVID-19 pandemic on the socially vulnerable, especially on those who are with disabilities?

In his speech, Dr. Rao presented research on past pandemics showing disabled people find it harder to access critical medical supplies and support during critical times - which can become even more challenging as resources become scarce. This proved true during the **COVID-19** pandemic when studies have shown an increase in the percentage of patients whose degree of physical disability was not assessed or recorded at the time of diagnosis.

Dr. Rao also brought research showing the development of leprosy reactions due to COVID-19 infection or after getting vaccinated against the disease. Finally, the researcher mentioned the long-term effects of COVID-19 on leprosy disabilities are yet to be fully understood.





Dr. P. Narasimha Rao

President of the International Leprosy Association and Indian Association of Leprologists

Testimony

"I was sick, really sick in the village, but not only me, my children too, at the same time. I had to provide for and take care of them despite my pain and sorrow."

"We arrived with only what we were wearing and what could carry on. By the grace of God, we recovered our health. The sisters healed not only our illness, but also our souls - because we were without hope."

Ms. Dimby and Ms. SoavinaPersons affected by Hansen's disease, Madagascar





"I'm working since 1994 (in the field of leprosy), so I have seen all the changes in the programs from the beginning."

"What about the rural population? From where I am coming, 89% of people live in rural areas. They don't have access to treatment. There are no holdings in the villages. So how can we say is a good awareness?"

Mr. Rajni Kant Singh State Coordinator for Bihar Operations, LEPRA Society, India

"The disease was progressing uncontrollably. It smelt so bad that everybody had abandoned me. People called me rotten fish."

"I'm currently doing a Master's degree, so life wasn't easy, but that's how it was recruited by Follereau Fondation. I am responsible for disability projects. My self-confidence has grown."

Ms. Paule Helena Biaka

Person affected by buruli ulcer, Cote d'ivoire





"The greatest support I received during the illness was from my children. I was already giving up on living with this disease."

"What would you suggest to doctors? Perhaps they should pay greater attention to people with leishmaniasis because it's a very painful condition and a very sad one. And try to treat sick people with all the intelligence in the world."

Mr. Juan Alberto López PadillaPerson affected by
leishmaniasis, Colombia

"Due to the negativity attached to this disease, persons affected by leprosy could neither get employment nor get an education. These circumstances let the victim be forced to leave his family and beg for livelihood."

"Persons affected by leprosy and their families are looking for opportunities, rather than donations and sympathy."

Mr. Sarang Gayadhane,Secretary of Association of
People Affected by Leprosy (APAL), India





"People affected by leprosy are faced with countless barriers from diagnosis to treatment, both in Brazil and everywhere."

"We have to come up with collective strategies that can ensure a better quality of life. The ultimate goal has to be that of ensuring that all people can live with dignity. They're not just arms or fingers or just numbers or figures."

Ms. Patrícia Gonçalves SoaresCoordinator of the Department of Policies for Women, Morhan, Brazil

Best Practices

with special attention to the roles of religious organizations

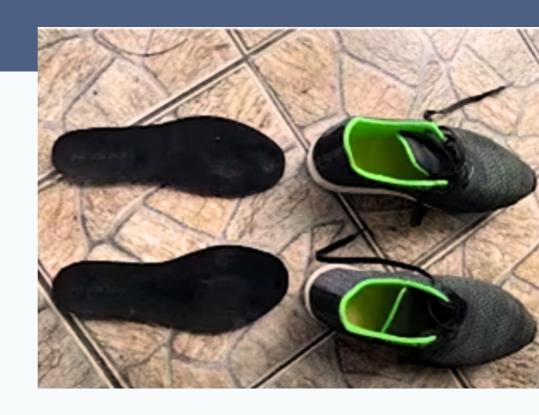
To conclude the International Symposium discussions, a group of representatives from religious organizations brought to the table their perspectives on the theme of the second day. The session was moderated by Mr. Patrice Simonnet, Director General of AIFO.

Mr. Thierry zen Ruffinen,
President of Fondation
CIOMAL de l'Ordre de
Malte, structured his
argument around the idea
that "successful actions of
the past can be applied in
this day and age, as well".

Mr. Ruffinen explained that CIOMAL was created in 1099, with the first hospital, in Jerusalem. In 1530, the Order of St. John arrived in the Maltese Islands, becoming one of the best hospital centers until the 18th century. CIOMAL (Order of Malta Leprosy Relief), properly, was created in 1958, in Geneva.

The speaker also presented the case study of Cambodia, in Asia, where CIOMAL managed to reduce 100 times the number of leprosy cases, in 20 years. And also the innovative custom-made 3D printed bespoke orthopedic shoes, unveiled at the last World Leprosy Congress, in India, by Alliance Against Leprosy. "This technology can change lives. It's useful in treating the disease complications and it's also useful in terms of the social reintegration of patients."

Next, Sr. Sabine Ramasinoro, Head of Marana Centre, Madagascar, gave her statement. Sr. Ramasinoro reported the organization serves approximately 100 people, who either go home or are hosted by Marana Centre. The organization also offers social rehabilitation programs and vocational training courses, as well as takes part in awareness-raising campaigns.

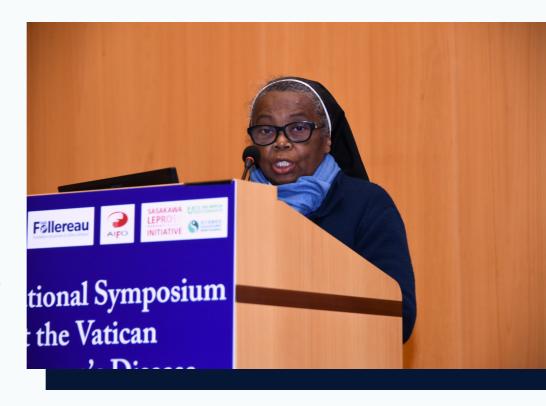


"The first thing we must do is recognize that they are human beings. And this is what we do. We clean them up, we dress them up even before screening them. So once we have a confirmed leprosy diagnosis, we can provide them with treatment, food, shelter."

Sr. Ramasinoro also explained that Marana
Centre operates in terms of brotherhood. "We help each other just like a family. We have common toilets. No one helps us, so the patients themselves help us to tidy up and clean up. But, at the end of the day, we are a family."

Dr. Jose Manikkathan,
Director of **AIFO India**, also
gave his speech. Amici di
Raoul Follereau, acronym
AIFO, was founded in
Bangalore, India, in 1998, as
the national coordinating
office. They belong to the
First Order or Franciscans in
Catholic Church. AIFO India
supports over 40 NGOs in
the country, as well as
Bangladesh, Myanmar
and Nepal.

The Director of AIFO India also explained the challenges of the northeastern states of the country.



The majority of population is tribal and faces low quality of life. These are regions difficult to reach, where leprosy cases are detected in advanced stages. Most patients have deformities - including children. "Any parameters of quality of life you take are very low. (...) I'm sorry to say that most of the international leprosy agencies also neglect the Northeast part of India."."

AIFO India offers welfare activities, supports affected children to continue their studies, and facilitates local and state-level organizations in national coordination.

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Sr. Sabine Ramasinoro, Head of Marana Centre, Madagascar The next to speak was Sr. Bawani Chelliah. Order of Franciscan Missionaries of Mary, Sri Lanka. The order has three centers in the country: Hendala, Manthivu and Badulla. "There are many people affected by leprosy who live in hospitals, today. They have no place to go. They are elderly, spending the evening of their lives in the hospital. Some of the residents do not have families to visit them and too many have been left. So, the sisters visit them, listening to their stories and helping them in any way they can. To make them feel that they are not alone."

In addition to hospitals,
Order of Franciscan
Missionaries of Mary also
serves communities, where
distribute medicine and
nutritional supplements. "The
sisters give something more
valuable than even
provisions. They give a
listening ear. People with
leprosy share their stories,
feelings and fears with their
sisters, in confidence."

The last speech was from Sr. Gladis Estela Llano Uribe, Director of Villa Bernarda Foundation, Colombia. Their Community-Based Rehabilitation strategy has an emphasis on socioeconomic development and social inclusion.

The Community-Based Rehabilitation strategy is divided into five areas: health, education, facilities, full participation in social life and the empowerment process. This means a complex range of activities, such as: creating opportunities; building capacities, supporting and working with organizations of persons affected; involving intersectoral groups; promoting the leadership and participation of local governments; and using the legislative and social systems of global practices as standards.

"We can support and work with the support groups."



"The sisters give something more valuable than even provisions. They give a listening ear."

Sr. Bawani Chelliah, Order of Franciscan Missionaries of Mary, Sri Lanka

Recommendations and suggestions
What roles do leprosy stakeholders play? How do they work?

Perspectives

of key actors from the Global Leprosy Community

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Dr. Vivek Lal

Team Leader of Global Leprosy Programme, WHO

- WHO will formally publish the Leprosy Elimination Framework and continue to support the Member States to make the Global Leprosy Strategy 2030 actionable through the development of country-led and country-owned Zero Leprosy Roadmaps, to achieve interruption of transmission and elimination of the disease.
- WHO will continue to encourage Member States to provide data, including nil reporting, and establish a formal process to acknowledge countries that claim to comply with the indicators devised under the framework.
- WHO will facilitate research and development on new diagnostics and drugs and their adoption in the context of a defined strategic approach...
- WHO will continue to take action to increase the access to tools already available to us, such as the single dose rifampicin, post-exposure prophylaxis and integrated skin entities approach.
- Most importantly, what we also see in these conference, is to foster a greater collaboration and cooperation among Member States, partners, donors, institutions, experts and the networks of persons affected by leprosy.
- The nucleus of it all, the most important: promote empowerment and meaningful participation of persons affected by leprosy.

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Dr. Alice Cruz

UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members

- One important lesson that perhaps we can take is that
 we do not have a follow up mechanism to this international
 event that would allow us to identify their
 impact at the ground level.
- We are very effective in creating guidelines, in creating recommendations standards at international level, but I believe that we still have more work to do to bridge that to people's lives on the ground.
- I do not have the resources to implement any follow-up mechanisms. Perhaps what I said in my keynote speech about creating a task force of people from the organizations of persons affected by Hansen's disease that could monitor all these processes at the national, local, but also international level might be interesting. A sort of a watchdog.

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Dr. Margarida Cristiana Napoleão Rocha

Technologist at the Ministry of Health, Brazil

- The most important aspect of our national strategy is the fact
 that it was built together with people who are affected by
 Hansen's disease. We have the active participation of many
 people who are here in drafting the strategy, along with a
 number of other stakeholders, including municipal representatives,
 state representatives and representatives
 from the Ministry of Health.
- We believe that a joint collective document can lead to empowerment so that these people can become empowered.
 And, ultimately, we will all have a role to play in this strategy we are promoting (in Brazil). So again, this is a strategy that is based on the Global Leprosy Strategy and it implements a number of recommendations.

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- We have made a lot of progress since the first meeting, in 2016, despite challenges with COVID-19. It is also clear that there's still a lot to do.
- I think at the last meeting one of the things that were called for was a unified approach and I think largely the Global Partnership for Zero Leprosy has come in to fill that role. I think that, for countries, we have an obligation to also translate that at the national level to make sure that we form those national partnerships. We have those National Roadmaps and not just at the roadmaps, but tap that collective action to make sure that the impact would eventually be felt. And not just to deal with the people we know, but to make sure that everybody that matters is at the table, including persons affected by leprosy.

Dr. Benedict Quao

Programme Manager of the National Leprosy Control Programme, Ghana

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• The question that I'm tackling is: **what are we doing towards zero leprosy**, specifically in relation to the recommendations and conclusions that came from the 2016 sumposium here in the Vatican?

- First, it was stated in 2016 and you've heard it several times: every new case of Hansen's disease is one case too many and we certainly embrace that view. Some of the key targets in the WHO Global Leprosy Strategy 2021 2030 are pretty challenging targets, but we think may be achievable with the rapid and widespread uptake of existing tools and the development of new tools to combat the transmission of the disease.
- Second point: the big reduction in case numbers that are envisaged in the Global Leprosy Strategy is challenging, but eliminating leprosy-related stigma and discrimination is a whole lot more challenging. And as you've heard from some of the presentations, the ILEP members are working to enable education and livelihoods and the formation of self-help groups and other sorts of activities that are known to combat the negative effects of social exclusion.
- Third point: ILEP maintains a database of all known discriminatory laws and regulations which still exist, in far too many countries. So ILEP and our member agencies will continue to call for repeal and amendment of these laws. But it's a long road and sometimes often those calls fall on deaf ears. So we invite all stakeholders in this sumposium to take up the challenge to talk to us.
- And final point, let me quote from one of the recommendations from the 2016 symposium. Persons affected by leprosy must be seen as the main actors in the fight against discrimination and the denial of rights that they experience. ILEP is been impressed and encouraged, actually, to see since 2016, how people's organizations are increasingly effectively and powerfully advocating for themselves at the local and national level and international levels. But, in some countries, these organizations either don't exist or they're very fragile. So we want to work productively and respectfully in dialogue with persons affected by leprosy to understand how best we should support the birth and the nurturing of such organizations and a path towards a greater autonomy, empowerment and capacity.

Mr. Geoff Warne CEO of ILEP

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Mr. Bill Simmons

CEO of American Leprosy Missions and Chair of Global Partnership for Zero Leprosy (GPZL)

- I might look to the example of Luke 17 if you might allow me. Jesus is on his way toward Jerusalem. He's traveling through Samaria, and he is about to reenter Galilee when he encounters a story. I'm sure many of you are familiar with ten men who, according to Scripture, had lepra. Now, this audience is well aware that unlikely that these men had Hansen's disease, but that's not the point of this example that I wish to leave with you today. The inspiration that I take from the example of how Jesus approached these ten men helps drive our focus toward what it means to reach zero leprosy. So the example that he laid out for us in the dust of Palestine 2000 years ago.
- As he approached these ten men, they, of course, said: Lord, have mercy upon us. You're aware that he encouraged them to present themselves to the priest. And, as they went, the scripture says they were cleansed. But then one man returned having been healed and thanked Jesus. And so this story tells me something about how we should approach our work towards zero leprosy. There are three points: one has to do with access, one has to do with healing, and one has to do with inclusion.
- The very first thing Jesus did was bring access to health to them. He met them where they were. Access to health is one of the very first objectives we have in reaching zero leprosy. The second thing, of course, was healing. He brought health to these men. That is the goal that we have in our world, right, that people affected by leprosy would have health and then are included. The very interesting thing that Jesus did here, he does nowhere else in the New Testament. He sends men to the priest and that is because the only way they could be re-included in their society and their families was to have the priest endorse the healing. So he not only cared that they were healthy, but he cared that they were included.
- We can take heart from this example that we must continue to work to ensure that people have access to healthcare, that they have the tools so they can be healed and, most of all, that they can be included in the lives of their community and the families.

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Dr. P. Narasimha Rao

President of the International Leprosy Association and Indian Association of Leprologists

- I like to concur with the conclusions given in the 2016 recommendation that every new Hansen's case is one case too many, and every case of stigma and social exclusion is one case too many, and every law that discriminates against persons affected by Hansen's disease is one law too many. But regarding the 4th point, I looked elaborately. The 4th point reads as follows: 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.
- At this point, I would like to share the opinion of mine and of my association, because I work in India. As rightly mentioned by some of the speakers, there is a serious explosion of new cases in India and many parts of the world. One more thing which is troubling us is that more and more leprosy patients are now becoming multibacillary. In India in the 1980s and 90s, the percentage of multibacillary cases was around 30%. As, of now, it is crossed 55%. With that being the case, there is a need to probably modified the 4th recommendation, which I suggest as follows: there is a need to develop tools and harness technologies for early diagnosis of leprosy.
- Second, as a rider, I also suggest that we add, to facilitate
 it, that active case detection should be encouraged
 for early diagnosis.

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

- I would like to offer the perspective of someone who did not have the privilege of being part of the 2016 symposium and who is looking at this very much with fresh eyes, and knew not to leprosy but to the symposium, and who took the exercise quite literally of looking at the recommendations.
- What is the impact that we want to see from these five recommendations? Create a space for each of them to have this question asked. Consider prioritization, because when everything is a priority, then nothing is a priority. When that goes, then, allows us to understand who are the target audiences. Who are the agents of change? Who are the individuals that have the expertise to contribute to these priorities? How do we set up the monitoring to understand if we're succeeding? And, more importantly, what are the barriers that are keeping us there?
- I'd like us to also consider that maybe we have actually been making very strong achievements. My curiosity when I looked at this with fresh eyes was here are five recommendations. Have we landscaped and understood what achievements have been made? Because I'm sure they're there. And again, this goes back to a question of communication and dissemination, tracking and telling all of the stories that we're doing. But being able to do it within a structure that really supports if we're moving forward in these five recommendations.

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Ms. Letícia Cezar da Frota

Miss World Brazil 2022

- In Brazil, and we all know how hard it is, a beauty queen without a cause is purposeless. **Beauty must have a purpose and that's why I choose the Miss World pageant. My mission is to inform people wherever I go about Hansen's disease.** Believe it or not, many people believe it's something of the past. But it's not. It's real, and it's closer to us than we can imagine. Many people are still struggling not only with Hansen's disease, but also with the prejudice it carries.
- As Miss Brazil, I have visited former colonies in the Amazon where I live. And I wished to meet people there, talk to them and also understand what their needs are. I also talked to the children and I explained to them about Hansen's disease. I believe they are the best channel to reach their parents and other relatives. I was in India and understood that being Miss Brazil and having the lovely Miss India by my side helped to attract more media to the Global Forum, getting our message to the world. Soon, I will travel to Kenya to do the same.
- I must add I'm not alone. State and regional actors are also volunteers in this important cause. Together, we are much stronger. And, now, I travel not just in Brazil, but also around the world to inspire others to do the same.
- I dream that one day we will reach zero Hansen's disease target. With love, education and empathy. We can always do a lot more for this cause.

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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

- My suggestion is that persons affected by leprosy should be included in the government planning whatever schemes the government has. So the persons affected should be part of that process, not at the end of it, but throughout the process.
- Whatever we have discussed in (Global Forum) in Manila, there was no follow-up activity that has taken place. We discussed the same thing in Hyderabad, this time a few months back, and I feel that this is my suggestion: we should form a core committee at the international level to discuss and take follow-up actions.
- All the ILEP agencies and the representatives of all the countries present at the Manila conference should submit a letter to the government. They should also sign that because if so many country representatives sign that will be pressure on the government about the recommendations and suggestions.

Perspectives

of the Organizers

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Mr. Patrice Simonnet
Director General of AIFO

- The global appeal of this symposium is an important message.
 We will convey it, but let me give a few points
 as perspective perhaps of a newcomer.
- The first one is we say don't forget, but there is a new generation. There's no way they don't forget because they need to know. And it's our responsibility to explain better what are the entities, and what is a disability, poverty. We need to do more awareness and more communication. (...) We need to explain better what we are doing here all together because at one point we are struggling for funds very, very often when we are speaking today of Hansen's disease. So we need to communicate.
- My second is to go on working altogether. I spoke about civil society volunteers in our countries. For sure we see the importance of Mr. Brazil could have in our country. We don't have Miss Italy, but we'll try and perhaps one of the volunteers could be anyway, so we have to invent that kind of communication tool or any kind of engagement or volunteers will be on the 29th of January in the churches getting phones from the people going to the church to mass and I thank them. We have more than 500 volunteers and perhaps during the day of leprosy thousands and but we need more young people, we need to re-communicate with them. We will. We need people, we need networks. We need our staff, our staff is important and we need people qualified. We need people that have studies and know what are the challenges.

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Mr. Oleg Ouss CEO of French Raoul Follereau Fondation

- I have three things to share with you. First of all, how important it is to have a holistic approach. Secondly, how important it is to take advantage of our strengths as much as possible, and thirdly, how important it is to allow all people involved in the struggle to participate in our actions, and we understand that.
- Allow me to express my disappointment with the fact that many
 people affected by Hansen's disease were refused visas. When
 you travel from a continent like Africa, when you are poor,
 sometimes you don't have the same rights that others have,
 including the right to travel. Now, I don't want to judge our
 governments. I don't want to judge our states.
- As Raoul Follereau said, it is important to question things, to build things and, hopefully, through our revolt, through our rage, we can build love. And I think that I have to work on myself to turn my disappointment into love. I don't know what the solution is, but I'll work so that in the future we will be able to allow other people to travel to Europe so that they can share their experiences.

Dr. Takahiro Nanri

Executive Director of Sasakawa Leprosy Initiative

- I'm going to present how we, as the Sasakawa Leprosy Initiative, are going to respond to the five recommendations adopted at the previous conference in 2016.
- Sasakawa Health Foundation/ We have three pillars of activities: 1. tackling the disease; 2. eliminating discrimination; 3. preserving history. And I would also add awareness raising because, in responding to the five questions, I think we need to talk about awareness raising too.
 - First, tackling the disease. The 2016 recommendation says contributing to further scientific research to develop new medical tools to prevent and treat leprosy. So, our response is one, we have been working with the World Health Organization for the past 50 years and, currently, we are supporting around 40 countries. And, of course, we continue this effort. But, at the same time, there are some important networks, like Global Partnership for Zero Leprosy, ILEP. To enhance the quality of activities in each country, we want to promote a partnership or collaboration among those governments and the keu stakeholders, the members of the those networks.
 - To enhance the quality of activities in each country, we want to promote a partnership or collaboration among those governments and the key stakeholders.
 - The second point is **contributing to further scientific research** to develop new medical tools to prevent and treat leprosu. No funds are currently available, but we have already developed a project to establish the rapid diagnostic method to detect **rifampicin resistance** and given that step is being implemented in many countries. So we continue this kind of effort.
 - We also want to maximize the presence of our WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa. Whatever strategies, whatever action plans are coming up with, we need a political commitment to move forward. So we want to maximize the activities of our Goodwill Ambassador to obtain political commitment globally, at the country level and local levels.

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- Second pillar: eliminating discrimination. The recommendation says the implementation of the Principles and Guidelines (for the Elimination of Discrimination against Persons affected by Leprosy and their Family Members) and also the modifications or average abolition of all discriminatory laws and regulations.
- So, how do we respond? First, we continuously support the empowerment of the persons affected by leprosy. We have been engaging in such kind of work for the past 30 years or so, and up until now we already worked in 25 countries. And, at the same time, we are also considering a new program to continuously discover new leaders and provide them relevant training to strengthen the community as a whole.
- We also would like to support research to investigate the current situation of stigma and discrimination surrounding the patients affected by leprosy. Why? Because that information sure will be a very important resource to convince the government to come up with a proper implementation plan for the Principles and Guidelines. Last year, we supported the initial survey project in 8 countries, so we are currently considering expanding the project.
- We continue to advocate to the international community that
 the persons affected by leprosy should not be left behind. So,
 for instance, we continue to advocate to the United Nations
 Human Rights Council, and the conventions in the light of the
 patterns with disabilities. And, of course, we can continue to work
 with the United Nations Special Rapporteur.

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• The last pillar is historic preservation. History preservation is not included in the five recommendations. But, based on our experience, we figured out that preserving history will promote social transformation by fostering greater respect for the dignity of the persons affected and also it will enhance the quality of leprosy services, in various ways. So, I think preserving history could make it an engine to accelerate other pillars.

- So, for instance, we have already conducted activities to create
 a model of the historic preservations in Asia and Europe; and we
 are now trying to initiate similar kinds of activities in Latin
 America and Africa, in the countries like Colombia, Brazil, maybe
 Ethiopia or Nigeria. And we are also operating the national
 Hansen's Disease Museum in Japan, constructed by the
 Japanese Ministry of Health. We will continue these initiatives.
- The second part of historic preservation is creating the archives and organizing the International Conference. We have already established and maintained a history of leprosy website, in collaboration with International Leprosy Association. And we have already organized an international symposium on the preservation of the level of history five times. So, we will continue to work in this area actively, too.
- Finally, awareness raising. The recommendation says spread in our industry leprosy is curable and the stressing that there is no reason to discriminate. So in response to this, we will continue the Don't Forget Hansen's Disease campaign globally as we will continue to deliver the message that leprosy should not be forgotten. We also continue the Global Appeal, by using the occasion of World Leprosy Day. Our tactic is to expand beyond the leprosy community. We need to encourage newcomers to get into our community.
- Sasakawa Leprosy Initiative believes that unified and joint plans of cooperation should be developed. We will continue to organize the international symposium, like this one, and create a venue for the key actors of the global leprosy communities to get together and discuss ways for collaboration. So this conference is one of the examples. And we are going to organize another big conference on leprosy on June 21st to 22nd in Bergen, Norway, on the occasion of the 150th anniversary of Doctor Hansen, who discovered the agent of leprosy.

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Mons. Charles Namugera
Dicastery for Promoting
Integral Human
Development, Holy See

- Integral human development is about a person-centered approach. That is not a new concept in the mission of the church. It has been around for ages, but it gets more articulated with time. For development to be called or known as authentic, it must be well-rounded, it must foster the development of each person and the whole person. What counts for us is each person, each human group and humanity as a whole.
- As Pope Francis reminded us, World Leprosy Day should be an occasion to review our models of development and to denounce and seek to correct the discrimination they cause. The rich experiences that have been shared have shown us that we have to use a holistic or raw, wellrounded approach, a multidimensional approach since the problem we are addressing has multiple aspects to be addressed at various levels.
- We realize that integral human development or authentic development cannot be done by one actor alone. It needs the concerted effort of people working at different levels from different angles to respond to the mild dimensional needs of a human person.
- And that is what our person-centered approach is about. It
 makes us aware that we cannot be single actors. We
 need to collaborate, to work together to come up with
 an effective approach that can help us to reach zero
 discrimination, zero transmission and zero disability.

Program

International Symposium at the Vatican on Hansen's Disease "Leave No One Behind" and Global Appeal 2023

DAY

Y 1: Mond	lay, January 23, 2023
9:00 - 10:00	Registration
10:00 - 10:05	Opening Prayers
10:05 - 10:10	Message by His Holiness Pope Francis
10:10 - 10:35	Greetings from the Organizers Sr. Alessandra Smerilli, F.M.A., Dicastery for Promoting Integral Human Development, Holy See Dr. Pierre-Yves Łiebault, President of French Raoul Follereau Fondation Mr. Antonio Lissoni, President of AIFO Mr. Yohei Sasakawa, Chairman of the Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination
10:35 - 11:10	Messages from Dignitaries Mr. Francisco Faustino Pinto, National Vice-Coordinator of Morhan, Brazil H.E. Dr. Michael Mann, Ambassador of the Sovereign Military Order of Malta Mr. Tim Hughes, Deputy Executive Director of the International Bar Association Prof. Margareth Hagen, Rector of the University of Bergen, Norway (video) Mr. Volker Türk, United Nations High Commissioner for Human Rights (video) Dr. Tedros Adhanom Ghebreyesus, Director-General of WHO (video)
11:10- 12:00	Launch of the Global Appeal Special Video Message from Mr. Yohei Sasakawa, Chairman of The Nippon Foundation and

WHO Goodwill Ambassador for Leprosy Elimination

Reading of the text of the Global Appeal 2023 by Ms. Letícia Cezar da Frota, Miss World Brazil 2022

Photo session

12:00 - 13:30

Press Conference - Organizers & Representatives of persons affected by Hansen's disease

Theme: Toward Zero Leprosy

Keynote Speech: Addressing the Current Situation and Remaining Challenges in Leprosy, 13:30 - 14:00

Six Years after the Adoption of "Conclusions and Recommendations"

Dr. Ibrahima Socé Fall, Director of the Department of Control of Neglected Tropical Diseases, WHO Dr. Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members (video)

14:00 - 15:20 Session 1: Zero Disease & Disability

Moderator: Dr. Vivek Lal, Team Leader of Global Leprosy Programme, WHO

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

Dr. Paul Saunderson, Technical Advisor of American Leprosy Missions

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

Dr. Anil Kumar, Additional Secretary General, Ministry of Health and Family Welfare, India (online)

Dr. Benedict Quao, Programme Manager of the National Leprosy Control Programme, Ghana

Ms. Lucrecia Vasquez Acevedo, President of Felehansen, Colombia

Panel Discussions

15:20 - 15:50 Coffee Break

15:50 - 17:10 Session 2: Zero discrimination

Moderator: Dr. Takahiro Nanri, Executive Director of Sasakawa Health Foundation/ Sasakawa Leprosy Initiative Panelist: Mr. Brent Morgan, International Director of Le Leprosy Mission International and President of ILEP

Mr. Gaurab Sen, CEO of Sasakawa-India Leprosy Foundation

Dr. Margarida Cristiana Napoleão Rocha, Technologist at the Ministry of Health, Brazil

Dr. Tanzina Islam, Deputy Program Manager of the National Leprosy Program,

Ministry of Health and Family Welfare, Bangladesh

Mr. Tesfaye Tadesse, Managing Director of Ethiopian National Association of Persons

Affected by Leprosy (ENAPAL), Ethiopia

Mr. Al Kadri, Chairman of PerMaTa Indonesia

Panel Discussions

DAY 2: Tuesday, January 24, 2023

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

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 aected by Hansen's disease, Madagascar (video) Mr. Rajni Kant Singh, State Coordinator for Bihar Operations, LEPRASociety, India (video) Ms. Paule Helena Biaka, A person aected by buruli ulcer, Cote d'ivoire(video) Mr. Juan Alberto López Padilla, A person aected by leishmaniasis, Colombia Mr. Sarang Gayadhane, Secretary of Association of People Aected 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
11:15 - 12:45	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 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 ARected by Leprosy (APAL), India and the representativo of the 2nd Global Forum of People's Organizations on Hansen's Disease Q&A session
15:25 - 15:55	Coffee Break
15:55 - 16:45	Session 2: Perspectives of the Organizers 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 Mons. Charles Namugera, Dicastery for Promoting Integral Human Development, Holy See O&A session