

# FOR THE Elimination OF Leprosy

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place



The Goodwill Ambassador speaks with Pope Francis during a Papal Audience in St. Peter's Square in Vatican City on June 8.

MESSAGE

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## Religion's Reach

As the WHO's Goodwill Ambassador for Leprosy Elimination, I strive to convey correct information about leprosy by sharing three simple messages all over the world: leprosy is curable, treatment is free, and social discrimination has no place.

Since I launched an annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy in 2006, the appeal has been endorsed by influential individuals and organizations ranging from Nobel laureates and religious leaders to the World Medical Association, International Bar Association and International Council of Nurses.

Among these, I believe that the world's faiths have the most important role to play in raising awareness, since they touch so many lives. There is also a history of religious figures such as Saint Damien and Mother Teresa having very close contact with and deep empathy for people with leprosy.

My father Ryoichi Sasakawa was invited to the Vatican in 1983, where he had an audience with Pope John Paul II and promised to eradicate leprosy from the world. I accompanied him and it remains a vivid memory. Later I would have the opportunity to

meet Pope John Paul II again in 2002, and explain the current leprosy situation.

Most recently, in response to my request, the Pontifical Council for Health Care Workers agreed to jointly organize with The Nippon Foundation a symposium on leprosy at the Vatican in June. The two-day meeting brought together people affected by leprosy, human rights experts, NGOs, the WHO and representatives of the Catholic Church and other major faiths from 45 countries. For a conference on leprosy, it was without precedent.

Participants gave their assent to Conclusions and Recommendations that include a strong call to end discrimination. It is more than I could have dreamed of that these will reach the world's 1.2 billion Catholic faithful.

It is my hope that other religions will also position leprosy as an important, unresolved medical and social issue facing humankind, and work to spread accurate knowledge in order to eliminate the disease and the discrimination it brings.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# An Interfaith Call to Action

Vatican gathering urges religious leaders to help end discrimination.



The crowds in St. Peter's Square on June 12 at Holy Mass for the Jubilee for the Sick and Disabled

A recent symposium at the Vatican issued a call for leaders of all faiths to contribute to the elimination of discrimination against persons affected by leprosy as a matter of urgency, and condemned the use of discriminatory terminology that continues to reinforce old perceptions of the disease.

“Towards Holistic Care for People with Hansen’s Disease, Respectful of Their Dignity” took place during the special Year of Mercy designated by Pope Francis from December 2015 to November 2016. It formed part of the activities for the Jubilee for the Sick and Disabled that culminated in Holy Mass in St. Peter’s Square on June 12.

Around 200 people from some 45 countries took part in June 9-10 symposium, which was organized by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation and The Nippon Foundation, in cooperation with Fondation Raoul Follereau, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation.

They heard speakers covering 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 that the disease — and society’s response to it — has had on their lives.

## MEDICAL CHALLENGES

On the medical and scientific front, the current leprosy situation was reviewed by the team leader of the WHO’s Global Leprosy Programme, Dr. Erwin Cooreman. Some 200,000 new cases are reported to the WHO each year, and Dr. Cooreman said that each represents a case of disease but also a person who may be ostracized

from his or her community.

Dr. Marcos Virmond, the president of the International Leprosy Association, highlighted some of the key challenges to be overcome if leprosy is to be defeated. These included lack of government commitment and resources for leprosy control, lack of clinical expertise, and the need to break transmission of the disease.

Dr. Ann Aerts, CEO of Novartis Foundation, which donates the multidrug therapy (MDT) used to treat leprosy, stressed the importance of using new tools to accelerate diagnosis, while Dr. Stewart Cole, president of the Fondation Raoul Follereau’s Medical Commission, argued for a standardized platform for disease testing that would help to reduce stigma.

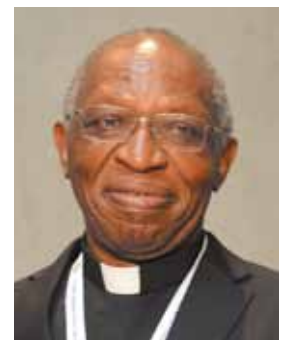
But beyond what these experts had to say about the epidemiology and science of leprosy, the real significance of the symposium for many lay in finding out what message would come from the Catholic Church and other faith communities with regard to fostering dignity and respect for persons affected by this disease and alleviating the discrimination and suffering they face.

In that regard, Mgr. Jean-Marie Mupendawatu, secretary of the Pontifical Council for Health Care Workers, spoke unequivocally when he said: “Many rules set by religions have been adopted by states. They are not always good. We are sorry; but saying sorry is not enough....We are all called to make up for this. There are practices that are not good, and we need to fight them.”

Abdel Latif Chalikandi, advisor to the Tawasul Europe Centre for Research and Dialogue in Rome, said that Islam rejects the idea that leprosy is a curse of God or the result of past sins, and that no disease is an excuse for abandoning family. But he acknowledged that “cultural and family pressures”



Chalikandi: Islam rejects the idea that leprosy is a curse of God.



Mgr. Mupendawatu: We are all called upon to make amends.





Organizers brief the press on the symposium's objectives.

and “selective quoting of the Koran” result in people being ill-treated.

On the issue of restoring human rights, the symposium noted that a critical step forward has already been taken with the adoption of a UN resolution on “Elimination of discrimination against persons affected by leprosy and their family members” in 2010, but that much work still needs to be done to see that accompanying Principles and Guidelines are fully implemented. “Practical measures are needed to cajole states to act,” said Dr. Obiora Okafor, chairperson of the UN Human Rights Council Advisory Committee, especially with regard to the scrapping of discriminatory laws.

**“Many rules set by religions have been adopted by states. They are not always good.”**

**PERSONAL TESTIMONIES**

Some of the most compelling presentations came from those best placed to talk about the disease: the people with first-hand experience of it.

Jose Ramirez, Jr., from the United States, who is a Catholic, recalled being given the last rites and taken by hearse from his hometown in Texas to



Different cultures and faiths come together at the Vatican.

a leprosarium in Louisiana after being diagnosed with the disease. “My mother believed that God was punishing her through me,” he said.

Maya Ranaware, from India, said that much has changed since she was humiliated at school for having leprosy and not allowed to stand in a queue to buy vegetables or ride public transport. Nevertheless, she added, “Most of us have inner fears of being rejected or not accepted by mainstream society. I must admit it is not easy to let go of this feeling.”

Attending from Japan, Masao Ishida described being involuntarily placed in a leprosy sanatorium at the age of 10. He is now 80. There were long years of “sadness, harshness and bitter experiences,” but through decades of activism he was able to regain his human rights. “I’ve walked my life path with Hansen’s disease. I didn’t have a choice. But it was far from being a life without meaning.”

From Colombia, Maria Eloisa Castro recalled how it took 20 years for her to be properly diagnosed. Today, the 80-year-old visits homes to explain to families what to do if they notice symptoms. “It is common to find health professionals who don’t know much about leprosy or who think it disappeared long ago,” she said.

Conclusions and Recommendations based on the proceedings were drawn up by Rev. Fr. Michele Aramine, professor of theology at the Sacred Heart Catholic University of Milan and presented in draft form at the final session. In addition to urging religious leaders to use their influence to spread understanding of leprosy and calling for an end to the use of discriminatory language that reinforces stigma, the document also recommends further research to develop new tools for prevention, diagnosis and treatment of leprosy. (See following pages.)

**‘A SHOWER OF BLESSINGS’**

Delegates who stayed on after the symposium ended were invited to attend the Holy Mass for the Jubilee for the Sick and Disabled celebrated by Pope Francis in St. Peter’s Square. A three-hour wait in the rain before Mass began — “a shower of blessings” in the words Kofi Nyarko of IDEA Ghana — did nothing to dampen their spirits. They also appreciated the fact that the Pope made special reference to Hansen’s disease in his remarks.

Nyarko, who had previously visited the Vatican for the canonization of Father Damien, was in no doubt as to the symposium’s significance. “The Catholic Church has a big role to play. What Pope Francis says goes all over the world. If he adds his voice to ending the stigma and discrimination, everything will have to change,” he said. ■

# Conclusions and Recommendations

Document makes important points regarding health, human rights, role of religious leaders.



Rev. Fr. Michele Aramine (left), professor of theology at the Sacred Heart Catholic University of Milan, presents the Conclusions and Recommendations.

The International Symposium on the topic, “Towards Holistic Care for People with Hansen’s Disease, Respectful of Their Dignity,” was jointly organized for June 9 to 10, 2016, at Vatican City by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation

and the Nippon Foundation in cooperation with the Fondation Raoul Follereau, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation. These Conclusions and Recommendations were presented at the end of the two-day symposium and were approved in principle by the organizers and the participants who were present.\*

substantial *risk of partly losing the expertise* that has been accumulated over recent decades by leprosy experts, medical doctors and health workers in relation to Hansen’s disease. Grants for study and training may be needed for service providers and caretakers including persons affected by the disease. Here, the principle, “Nothing about us without us” should be respected, and this is an important way of fighting against the stigma that is associated with Hansen’s disease.

A number of valuable recommendations in the presentations concerned methods to improve early diagnosis and promote the social integration of persons affected by leprosy. Public and private institutions should work in close cooperation with health authorities in each country to provide medical and health personnel with basic education about leprosy in order to strengthen leprosy programs within the framework of general health services. Efforts should be made to reintegrate communities of persons affected by leprosy into society. The message that leprosy is curable and can be treated while the patient continues to live at home should be emphasized.



The two-day symposium had a wide-ranging agenda.

## CONCLUSIONS

**1. Every new case of Hansen’s disease is one case too many.** It has been observed that new cases of Hansen’s disease are on the decrease and we should be very happy about this. But this decrease, which is in itself positive, could have resulted from *a decline in case-finding activities and reduced community awareness*. The increase in the rate of disabilities in new cases detected seems to support this explanation. Therefore, it is essential *to aim at early detection*. This applies to all new cases, *but particularly to child cases*. The WHO’s Global Leprosy Strategy 2016-2020 is moving in this direction.

A second cause for concern comes from the

**2. Every case of stigma and social exclusion is one case too many.** Stigma is often associated with a religious vision of life and it would be advisable to revise this belief. In reality, stigma has been linked from the earliest times with fear of a disease that cannot be defeated. Biblical texts of the Old Testament themselves record a practice of exclusion that was present in Egyptian, Assyrian-Babylonian and Canaanite cultures during the second millennium before Christ. The same fear is to be found in non-Christian and non-religious contexts.

The teaching of Christ in the New Testament, first of all, *breaks, with great clarity, the connection between illness and sin* (John 9:2-3). Secondly, *Jesus Christ touches people with leprosy, enters into contact with a sick person*

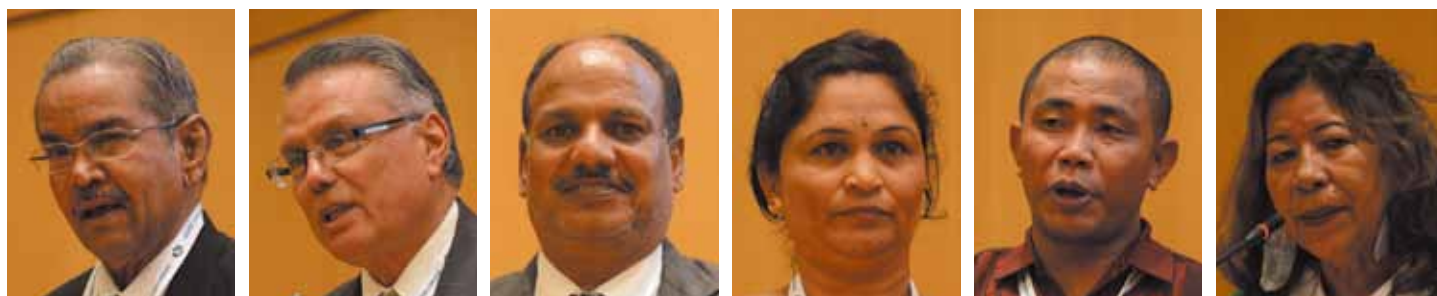
\* Note: While the terms “Hansen’s disease” and “leprosy” are used interchangeably in this document, in some countries the preferred term is Hansen’s disease.

## MEET THE MAIN ACTORS

The Conclusions and Recommendations state: “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.” Pictured here are 12 who made their voices heard at



*without any fear of contagion or impurity, and heals and reintegrates people into the community. Even more, he himself accepts being treated as if he had leprosy.*

The example of Christ has often not been followed — this neglect enables us to understand that it is easier to eliminate the disease at a medical level than the social prejudice that surrounds it. In this sense, it is absolutely necessary that we place the human being at the centre of all medical activity, rather than, as is often the case, placing the disease at the centre of attention.

*It is the teaching of Christ which has led Christians, especially over the last two centuries, to develop a high level of care and treatment for people with Hansen’s disease.* This took place even before pharmacological therapies were available, when care involved accepting and rescuing people and ending their state of abandonment. There is no need to recall here the giants of charity who were dedicated to this service. Today, as well, the Catholic Church remains strongly committed in almost all countries where the disease is found, to providing medical and humanistic care. Here a pathway opens up of cooperation with religious communities of other faiths and with all men and women of good will.

It is the shared opinion of experts who work in the field of Hansen’s disease that the elimination of the stigma attached to leprosy requires an important work of education that must involve all social groups and in particular religious communities because they promote respect for human dignity throughout the world.

**3. Every law that discriminates against persons affected by Hansen’s disease is one law too many.** Following intensive work, the General Assembly of the United Nations in December 2010 adopted a resolution on Elimination of discrimination against persons affected by leprosy and their family members, accompanied by ‘Principles and

Guidelines’. The resolution and ‘Principles and Guidelines’ constitute a *milestone in the upholding of the human rights of persons affected by Hansen’s disease.*

One must take into account that for every person with the disease, his or her family members and even relatives may also be ostracized due to the stigma attached to leprosy, resulting in a serious violation of fundamental human rights. An enormous amount of work still has to be done by governments and social and religious institutions to ensure that these ‘Principles and Guidelines’ are fully implemented.

*Unfortunately, various forms of discrimination continue to exist in many parts of the world which bear upon all spheres of life: schools, workplaces, social groups, public places, religious centres, restaurants, hotels, trains and other means of transport. Especially grave are the violations of the rights of persons affected by leprosy in the field of education, work, and marriage. The necessity to repeal discriminatory laws that impede fundamental human rights is very urgent and can no longer be postponed.*

**“(O)ld perceptions of leprosy continue to be reinforced by inappropriate language.”**

Implementation of the ‘Principles and Guidelines’ requires constant work involving the sensitisation of governments and societies. To this end, in 2012 the Nippon Foundation created a working group (the International Working Group, hereafter IWG), *which had the aim of assisting the process of implementation of the ‘Principles and Guidelines’.* The IWG prepared a “Suggested Framework for National Plans of Action” for States to use in their own domestic contexts.

The IWG came to the conclusion that the ‘Principles and Guidelines’ were more likely to

the Vatican. (Left to right): Dr. P.K. Gopal (India), Jose Ramirez, Jr. (USA), Vagavathali Narsappa (India), Maya Ranaware (India),

Paulus Manek (Indonesia), Valdenora da Cruz Rodriguez (Brazil), Du Chaoming (China), Kang Seonbong (South Korea), Kofi Nyarko

(Ghana), Masao Ishida (Japan), Seminiawa Bawik (Philippines), and Maria Eloisa Castro (Colombia).





be effective if States were called upon *to undertake specific ways of implementing them*, which could then be brought to the attention of various governmental offices and communicated to relevant UN bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions.

To this end, the IWG recommended *the institution of a follow-up mechanism* at an international level which would have the mandate to follow up the actions of States and other stakeholders, drawing upon the experience of Special Rapporteurs on various topics of human rights appointed by the United Nations Human Rights Council, or committees of experts which monitor the implementation of international human rights treaties and conventions. This follow-up work must not be neglected, otherwise there will be no perception of progress or steps back.

Accordingly, in the Resolution adopted by the UN Human Rights Council on 2 July 2015, the UN Human Rights Council Advisory committee is requested to submit a report containing practical suggestions for the wider dissemination and more effective implementation of the ‘Principles and Guidelines’ at the 35<sup>th</sup> session of the United Nations Human Rights Council in June 2017.

The IWG has observed, in particular, the need for civil society and religious communities to use dignified terminology when speaking about Hansen’s disease. It has been observed that the old perceptions of leprosy continue to be reinforced by inappropriate language. The offensive term ‘leper’ as a description of someone with leprosy evokes a marginalised person, a sinner, or a person who is rejected by other people for moral or social reasons. This terminology contributes to discrimination against persons affected by leprosy and even discourages those who need treatment from seeking help.

The IWG has thus invited religious leaders and their communities to reflect upon the best ways of expressing themselves in language that is able to transmit respect for persons affected by leprosy. Awareness-raising activities at the global level should make full use of new media to inform people about advances in treatment of leprosy and the fact that people who are under treatment or have completed treatment are not infectious. It is important that this information is available even in countries where leprosy is not an issue, in order to eliminate the myths surrounding this disease.

## FINAL 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. ■



The figure of St. Augustine that greets visitors to the Patristic Institute Augustinianum in Vatican City, where the symposium took place.

# In the Forests of Cameroon

The Goodwill Ambassador learns about the lives of the Baka people.



Visiting a Baka community in East Region

## CAMEROON (JULY 3-13)

In July I made my first visit to the West African nation of Cameroon. Cameroon achieved the elimination of leprosy as a public health problem at the national level in 1998. In 2014, it reported around 300 new cases; however, this figure must be viewed alongside the fact many parts of the country do not provide any data on leprosy, something I hope Cameroon will be able to address.

**Her eyes filled with tears and she told me she had contemplated suicide.**

After meetings in the capital, Yaoundé, with the WHO's country representative, Dr. Jean-Batiste Rongou, Health Minister André Mama Fouda and the national leprosy control program manager, Dr. Earnest Njih, I journeyed to East Region. I had come to learn more about the situation of the semi-nomadic Baka people inhabiting the rainforests in the southeast of the country.

The traditional Baka lifestyle has been affected by deforestation and increased hunting. There is also a policy to encourage resettlement and more Baka are starting to live near roads.

Based in Abong-Mbang, I visited several communities over the next two days. Among these, the first was Menzoh, where around 100 people had gathered to welcome me. I met three persons affected by leprosy there: an elderly man, a young boy, and a middle-aged woman whose body bore the marks of the disease. As the woman, whose name

was Adou, spoke about the hardships she had faced, her eyes filled with tears and she told me she had contemplated suicide.

I also visited Kwamb. A leprosarium was established here in 1936 after it was relocated from Abong-Mbang because locals there were afraid of the disease. There are churches and a school, and a community of around 200 people affected by leprosy adjacent to the hospital.

Among those I met at Kwamb, a middle-aged man told me he had developed leprosy as a child. He had received support from his immediate family, but had become distanced from his relatives and friends. He harbored hopes of returning to the forest one day.



Embracing a resident at Kwamb leprosarium

In Missoumme, the last community I visited, some way into the forest, I met two people affected by leprosy. When I asked someone who lived there why they thought these two had come down with the disease, I was told it was either a curse or God's punishment.

No matter where in the world one goes — even to a rainforest — the stigma associated with leprosy exists. This underlines the need for people everywhere to be properly educated about the disease and shows there is still much work to be done. ■

# P&G Progress Report

Draft report to UN body underlines need for mechanism to monitor implementation.

A progress report on the implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members was presented at the 17th session of the Human Rights Council Advisory Committee in Geneva on August 9.

The Principles and Guidelines were endorsed by a UN General Assembly Resolution in 2010, but five years on a Human Rights Council resolution adopted in June 2015 noted that people affected by leprosy still face multiple forms of discrimination.

Accordingly, the council requested its advisory committee to submit a report at its 35th session in June 2017 containing practical suggestions for the wider dissemination and more effective implementation of the Principles and Guidelines.

The advisory committee's progress report, prepared by Imeru Tamrat Yigezu, rapporteur of the drafting group on elimination of discrimination against persons affected by leprosy and their family members, includes the following recommendations.

At the national level:

- states and government institutions should strengthen, promote and facilitate awareness-raising campaigns and dissemination of the Principles and Guidelines, in collaboration with people affected by leprosy and their family members, and other relevant actors including educators and religious leaders.
- states should review and identify policies, laws and practices that engender stigma and



Advisory committee members gather testimony on the sidelines of a leprosy symposium at the Vatican.

discrimination and amend or repeal them.

- states should designate an appropriate body and establish a national committee in order to follow up and monitor effective implementation.
- states should ensure and support the full and meaningful participation of persons affected by leprosy at all levels of the decision-making process concerning actions that affect their lives.

At the international level:

- establish a specific and dedicated mechanism within the United Nations human rights machinery to follow up, monitor and report on the progress made by states at the national level toward the effective implementation of the Principles and Guidelines.

The advisory committee has requested the drafting group to submit its draft final report to the advisory committee at its 18th session, with a view to submitting the completed report to the council at its 35th session in 2017. ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### A HOPED-FOR OUTCOME

Cardinal Robert Sarah's detailed discourse on leprosy in the Bible and its association with divine punishment — "the plague par excellence with which God strikes sinners" — was a reminder for those attending a recent Vatican symposium of how deeply perceptions of leprosy have been influenced by its Biblical representation.

Notwithstanding the example of Jesus in the New Testament, who touches people with leprosy, heals them and reintegrates them into the community, the social prejudice that surrounds

the disease has proved hard to root out — despite the medical advances that have been made.

Tapping into the world's religions, especially the Catholic Church, and urging faith leaders to use their influence to help end the stigmatization of leprosy, was one of the goals of Goodwill Ambassador Yohei Sasakawa when he first proposed the Vatican symposium. In the Conclusions and Recommendations, the symposium duly issued such a call. Let us have faith its recommendations will be acted upon.