GLOBAL FORUM OF PEOPLE'S ORGANIZATIONS ON HANSEN'S DISEASE

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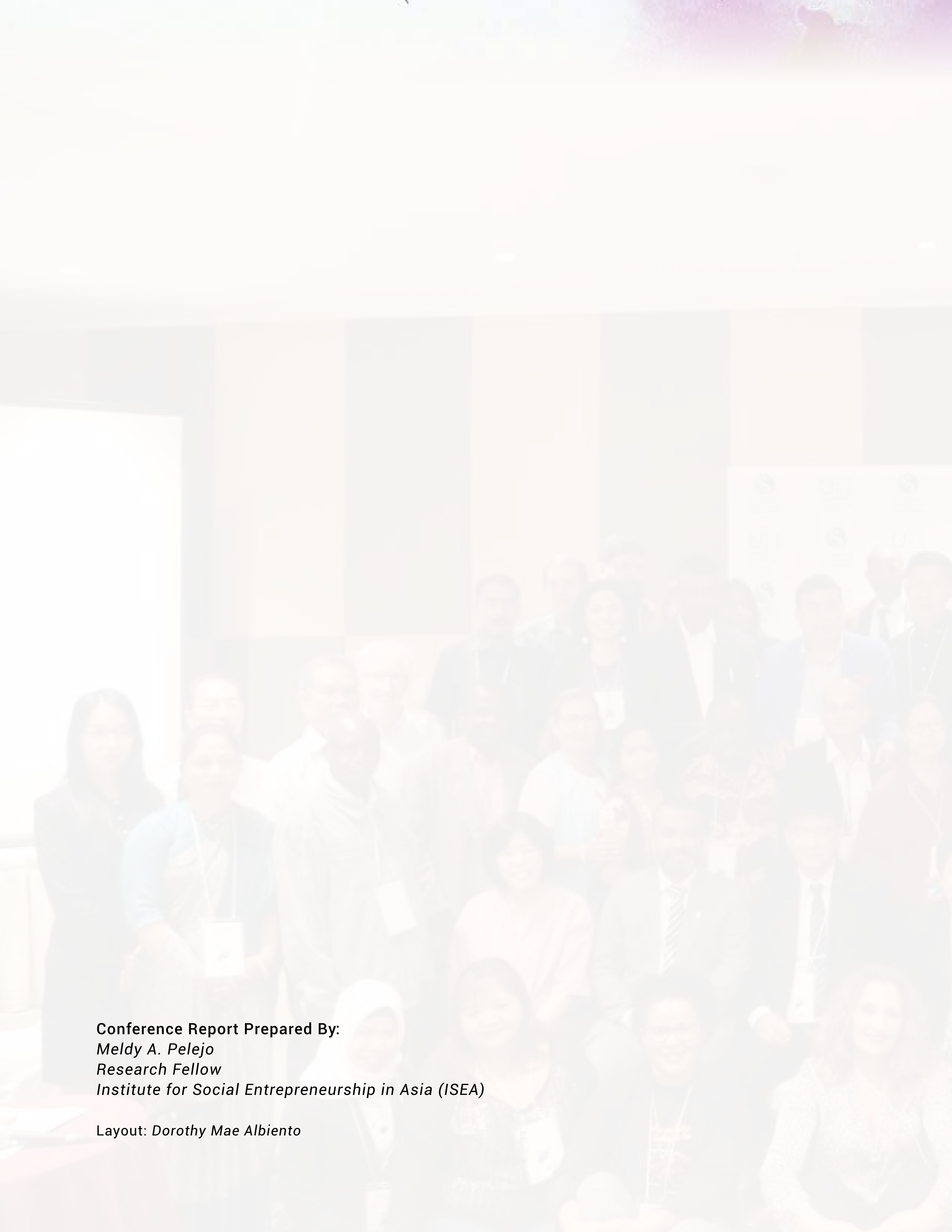

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ABOUT THE LOGO

The hand is a universal symbol of care. Thiago Pinheiro, a volunteer from Morhan, Brazil, who designed the logo for the Global Forum, envisioned that the hand embodies the hopes that the Global Forum will treat many issues needing more attention and thus, bring care and improvements for the whole world.

OPENING SESSION

WELCOME MESSAGE

Dr. Arturo C. Cunanan, Jr.

Dr. Arturo C. Cunanan, Jr.

Over the past decade, public health measures in the treatment of leprosy went through significant changes. Dr. Cunanan stated. In 1982, multi-drug treatment (MDT) was introduced. Global commitment, the adoption and resolution to end the stigma and discrimination against leprosy at the United Nations' (UN) General Assembly as well as the strengthening of the participation of people's organisations (POs) in providing leprosy services supported the elimination of the disease as a public health issue and to a significant drop in the number of new cases detected.

Despite these achievements, timely detection of new leprosy cases remains a challenge. The lowering of priorities and interests of public and private sectors in providing quality and accessible leprosy services are contributing factors.

The Department of Health (DOH) of the Philippines and the Culion Sanitarium and General Hospital has long recognised the need and importance of empowering these people and their organizations and assisting them to promote inclusion and respect for their dignity in ending the stigma and discrimination. There is also a growing interest and action on preserving leprosy's history so that future generations would have the correct information on the disease. This legacy needs to be made widely available as humanity's heritage.

> *It is crucial and there is a greater need for the active participation and wider involvement of people affected by Hansen's disease and their organizations in advocating for respect and upholding of their basic human rights.*

Sasakawa Health Foundation (SHF) and people's organizations see the importance of the first "Global Forum of People's Organizations on Hansen's Disease" towards building networks and sustaining partnerships with stakeholders. The next four days, he said, will provide delegates of the Global Forum with a people's perspective on Hansen's disease and how empowered people's organizations could help in overcoming the challenges in the last mile of the leprosy control program in their various countries.

On behalf of the organising committee, the DOH, the Culion Sanitarium and General Hospital, the SHF, Dr. Cunanan welcomed everyone to the Global Forum and wished them a safe, and comfortable stay in the Philippines.

DR. ARTURO C. CUNANAN JR. is currently the Medical Center Chief I of Culion Sanitarium and General Hospital, which was founded originally to treat patients with Hansen's disease. He has been the implementer of the Sasakawa Health Foundation (SHF) of Japan projects in Culion and in the Philippines related to Hansen's disease and human rights, preservation of Hansen's disease history, empowerment of people affected by Hansen's disease and their associations or groups and various socio-economic projects to improve quality of life of people affected by Hansen's disease and their families. He is also a consultant with the World Health Organization and has provided his leadership in reviewing the National Leprosy programs across the Micronesia region.

KEYNOTE SPEECH

Hansen's Disease in the Philippines: A Situationer

DR. MARIA FRANCIA M. LAXAMANA

Assistant Secretary of Health

Department of Health

Dr. Maria Francia C. Laxamana

Dr. Laxamana enthusiastically greeted all the delegates to the Global Forum with "Mabuhay and good morning!" She extended her special greetings to the Executive Director of SHF, Professor Takahiro Nanri, Dr. Huong Tran of the World Health Organization (WHO) Regional Office for the Western Pacific, Mr. Tesfaye Tadesse, Managing Director of ENAPAL Ethiopia, Mr. Francisco Onde, Chairman of CLAP; Dr. Alice Cruz, UN Special Rapporteur, Dr. Marie Lisa Dacanay, President of ISEA; and to Dr. Arturo Cunanan of Culion Sanitarium and General Hospital. She welcomed her fellow workers on Hansen's disease, the experts as well as the visitors coming from 23 countries. She felt honoured and glad to share her insights on the Hansen's disease program in the Philippines such as the best practices as well as good initiatives in the prevention and control of Hansen's disease.

Dr. Laxamana disclosed that she first visited Culion Sanitarium 20 years ago. Since 2017, she had been visiting the Sanitarium yearly. She hoped that all the delegates to the Global Forum could see the Culion Sanitarium and what the Philippines has achieved there. Culion now houses a museum, the Culion Sanitarium Museum, and is a UNESCO heritage. She believed it is worth emulating and sharing. She gave thanks to the efforts of everyone, especially to Dr. Cunanan, and hoped he could have an audio visual presentation made in order for everyone to see what has been attained.

The Philippines' Leprosy Program

As a country, the Philippines is aware of the misery resulting from Hansen's disease, Dr. Laxamana said. There are eight (8) sanitarias in the country and most of them have been upgraded to general hospitals. This move is one way of helping remove the stigma of the disease. All those afflicted by Hansen's disease and those with co-morbidities could be treated like any other patients availing of the general hospital services.

Although the country has been successful in eliminating leprosy as a public health burden, based on 2017 WHO data, there are still pockets of leprosy cases within the Philippines. This made the country one of those with the highest cases detected in the Western Pacific region. So far, the country has achieved a 3.6% reduction annually for new cases detected. From the new cases detected, Multibacillary Leprosy cases was at 94% or about 1,917 cases. She cited the delay in reporting or in active case finding as probable causes for the high rates. For this reason, the Philippine government is strengthening surveillance at the community, provincial, regional and national levels.

With regard to disability, the rate stood at 4% with a 2% reduction from the previous year. The decline indicates that self-care, prevention of impairment and disability are being addressed. Children below 15 years old have also been among the new cases detected though at a low proportion of about 4.6%. For the self-reported delays in seeking treatment, the duration of the delays ranged from 0 to 42 months with a mean of 25 months upon observation of the signs of leprosy. Of these, 49% of the cases sought consultation only after observation

DR. MARIA FRANCIA C. LAXAMANA is a graduate of medicine from the University of Sto. Tomas. She finished her residency training in anaesthesia at the Philippine General Hospital in 1992. She holds two Master's degrees: one in health services and administration with major in hospital administration, and another one in Community Services from the Ateneo de Manila University Graduate School of Business, which she completed in July 2000 and July 2001 respectively.

that the signs of their conditions have worsened. This would be an indication that stigma of the disease lingers, she added.

Universal Health Care Law

Last February 2019, the Philippines Universal Health Care (UHC) law was signed. She shared that this law would provide for the strategies, prevention and control measures to put aside the stigma of diseases. The law places a high emphasis on health literacy and health promotion. In fact, a bureau on health promotion will be set up at the DOH. More funds would also be given to health literacy, and will form part of the Department of Education's (DepEd) strategy. Health literacy will be included in the educational curriculum at the primary, secondary, and tertiary levels, an aspect that was left out in the previous strategy to prevent and control diseases in the country. Only 1 out of 4 cases would proceed to the health center as a second course of action. Dr. Laxamana reminded those gathered at the Forum that disabilities do not happen overnight but only after a prolonged period. Early detection has always been the key to achieve the targets and prevent leprosy transmission.

A key aspects of the UHC law is to ensure that all Filipinos are covered by universal health insurance. She shared that she had proposed that those who are afflicted with illnesses with the highest health burden such as psoriasis, Hansen's disease, and those with rare diseases be subsidized by the Philippine government. Presently, only those who live below the poverty line and the senior citizens receive subsidies. She requested Dr. Cunanan to help her in developing a position paper proposing that leprosy patients receive subsidies not only for their daily food allowance but also for their treatment and medicines under the UHC law.

Scaling Up Effective Strategies

Dr. Laxamana emphasized the importance of documenting the best practices and the strategies that have not worked well. Moreover, there is a need to scale up those strategies that have been found effective leprosy transmission. An intensified all-in inclusive approach would prevent thousands of infections every year. The UHC provides for a people-centered approach that is hinged on finding out the needs of patients, how to address those needs, and why diseases are not prevented. She then explained about the government's multi-agency National Leprosy Control Program. The DOH needs the help of the other government agencies: the Department of Social Welfare and Development (DSWD) to look into the housing of leprosy-afflicted families and the DepEd for the education of the children of those afflicted with the disease.

The Philippine government is using a Private-Public-Partnership (PPP) strategy to achieve its goal of a leprosy-free country by 2020. The aim is to lessen the disease burden while sustaining the provision of high-quality leprosy services for all afflicted communities while applying the principles of equity and social justice for all. She hoped that these efforts will decrease the number of endemic municipalities by 50%.

There is also a need to prioritize the areas where there are patches of leprosy incidence. The government's plan is to map the entire country to plot the places with the highest incidence of cases. Under the UHC,

In photos: (left) Dr. Cunanan, Dr. Tran and Dr. Nanri; (right) Mr. Faustinao Pinto with Ms. Chihiro of SHF.

In photo (left to right): Dr. Arturo Cunanan, Dr. Tauhid Islam, Dr. Maria Laxamana, Dr. Takahiro Nanri, Dr. Huong Tran

there will be population-based services and individual-based services. All population-based services will be subsidized by the government. This means that all Filipinos afflicted by a high disease burden would be fully supported by the government not only in terms of treatment, prevention and control but also in terms of prevention of future disabilities. For these reasons, the government has upgraded the eight sanitarias including Culion Sanitarium as general hospitals. These hospitals have been equipped with the needed equipment and machines such as dialysis machines, ultrasound, CTScan and MRI. In this way, people affected with the disease in communities will be treated fully in order to prevent further deformities and disabilities.

> ***We enjoin everyone and anyone to contribute what they can in the fight against the disease and disability.***

Those who have been afflicted by this disease are now seen as major players and partners in the fight against leprosy. They could help in spreading awareness, promoting early detection of the disease, prevention and giving cure to those who have contracted the disease." Adopting the primary care approach, the Philippine government will be enhancing the capacities of primary health care providers such as the community health workers, doctors and nurses deployed in the communities to enable early detection of different kinds of diseases, especially of leprosy.

Leprosy prevention and control in the Philippines has been sustained through quality management, treatment and addressing of the psycho-socio-economic burden in the country with the effective collaboration of different government agencies and private counterparts and development partners. Stronger and more meaningful collaboration between public and private sectors needs to be intensified for the continued development of the sanitarias, Dr. Laxamana advocated.

Those afflicted with the disease need support in reintegrating to mainstream society and living normal lives. There is also a need to lessen the stigma and to keep those in leprosaria relevant to modern conversations in social health and development. Telehealth is already mainstream at the DOH. It is being piloted in the island-provinces of Oriental Mindoro, Occidental Mindoro, Marinduque and Palawan where Culion is located. Once more, she reiterated her call to have an AVP on Culion Sanitarium that could be shared in medical curriculum or through virtual education at the country's College of Medicine.

As she ended her address, Dr. Laxamana urged all the participants to share the discussions in the Forum. She encouraged keeping the history of leprosy alive and the past lessons for future generations to benefit from them. With all these efforts, Dr. Laxamana stated, "we could build a brighter future for future generations since human history provides a unique perspective in order to develop a correct understanding of health problems in the community. Modern tools could be used to spread much needed information on how to deal with people who have been afflicted with the disease, how they overcame it, and how the disease will be overcome." She thanked everyone for patiently listening to all that she wished to share.

MESSAGE FROM WHO

WHO Remains Committed: Towards a Leprosy-free World

DR. HUONG THI GIANG TRAN

Director, Division of Programmes for Disease Control
WHO Regional Office for Western Pacific


Dr. Huong Tran

Dr. Tran felt very honoured to be present at the first Global Forum of People's Organizations on Hansen's Disease. She conveyed her warmest welcome and appreciation to everyone on behalf of Dr. Takeshi Kasai, Regional Director of the WHO Western Pacific.

The WHO's Global Leprosy Strategy for 2016 -2020: Accelerating Towards a Leprosy-free World was endorsed by WHO's technical committee advisory group on leprosy in 2015. The aim is to reduce the burden of leprosy at the global and local levels. This strategy has three (3) pillars:

- ◊ To strengthen government's ownership coordination and partnerships
- ◊ To stop leprosy and its complications;
- ◊ To stop discrimination and promote inclusion.

Leprosy Situation in the Western Pacific

In 1991, leprosy was successfully eliminated. In fact, leprosy prevalence has been declining over the years. In 2018, the registered prevalence rate for leprosy was at 0.04 % for every 10,000 population. The remaining challenge is to further reduce the case numbers in order to achieve zero-leprosy in the region. For many countries in the region especially the Philippines, Micronesia and Kiribati, leprosy is still a major concern. These three countries are in the list of the top 20 leprosy-stricken countries in the world.

> *People diagnosed with the disease and their families continue to face stigma and discrimination, which act as barriers to early case detection and treatment. Moreover, stigma limits the opportunity in life and leads to social and economic exclusion.*

She stated that the WHO Western Pacific region is highly committed to support community-based case screening, routine access and case finding activities, capacity building and promotion awareness activities. She commended the Philippine government's strong commitment to its national leprosy program. WHO greatly appreciates the organization of the first Global Forum of People's Organizations on Hansen's Disease. She said the high number of participants coming from 23 countries from around the world show the concerted commitment and solidarity to work for an inclusive society free from discrimination and stigma for leprosy. On this occasion, the WHO Western Pacific region recognised the efforts of The Nippon Foundation and the Sasakawa Health Foundation for their long-term commitment and strong support for leprosy for the past years.

Dr. Tran revealed that 25 years ago she had the personal experience of working with the Sasakawa Health Foundation. She formed part of the organizing committee when the International Leprosy Cogress (ILC) was held in Hanoi, Vietnam. She expressed how privileged and honoured she was to give the welcome speech in her new role as newly-appointed Director of Disease Control in the region. She reiterated that WHO is committed to provide technical support to leprosy countries and especially to maintain high regional staff for MDT. Dr. Tran ended her speech with wishes for a very happy and successful forum in the days to come.

DR. HUONG THI GIANG TRAN is a medical doctor and an associate professor from Vietnam. She holds a Masteral and Doctoral degrees in Public Health. Currently, she is in the Director for the Disease Control division of WHO's Regional Office for Western Pacific. This division handles all the expansion and immunization program for tuberculosis, leprosy, malaria, vector-borne disease control, neglected tropical diseases, and other non-communicable diseases.

MESSAGE

The First Global Forum: A Background

DR. TAKAHIRO NANRI
Executive Director
Sasakawa Health Foundation

Dr. Takahiro Nanri

Dr. Takahiro Nanri began with a hearty "Magandang Umaga" (good morning), one of the few words in the Filipino language that he learned when he worked in the Philippines many years ago. He expressed his great pleasure in meeting the participants of the first Global Forum of People's Organisation on Hansen's Disease. There were more than 60 representatives coming from 23 countries, which made it one of biggest gatherings. He thanked everyone for their support in making the conference happen.

The Nippon Foundation (TNF) and Sasakawa Health Foundation (SHF) had been working closely with people's organizations on Hansen's disease since the 1990s. The idea of holding the Global Forum came about in 2018 after they conducted a formal stakeholders meeting with the representatives of people's organizations. Three main ideas emerged from that meeting. First, for the representatives of people's organizations to make their voices heard and deliver their message at the 2019 International Leprosy Congress (ILC) where all the key stakeholders involved in leprosy will be gathered. Second, to ensure more productive discussions in the Forum, the idea of holding a discussion in each region also arose. As a result, the African assembly was held in Addis Ababa, Ethiopia; the Asia-Pacific assembly was held in Manila, and the Latin American assembly was held in Rio de Janeiro, Brazil from February to March early this year.

The agenda of the Forum was based on results of the three regional assemblies that he just mentioned. The role of the SHF is simply to provide the platform but it is up to the participants to decide how they will use this opportunity.

Dr. Nanri gave special thanks to CLAP and Dr. Cunanan for providing various support as host organization. He also thanked the ILEP member organisations that supported some participants to attend the Global Forum. SHF alone could not support the huge number of representatives of people's organizations to come to Manila, he said.

> *"Increasing skills to generate funds and partnering with other institutions are important steps to sustain and develop the organization."*

He hoped that as a result of the sessions lined up in the Forum, participants would get many ideas on how to develop their organizations thanks to the resource persons for the different thematic sessions: Dr. Alice Cruz, UN Special Rapporteur, who will speak about the challenges and issues on human rights. There will also

DR. TAKAHIRO NANRI is the current Executive Director, of Sasakawa Health Foundation and Associate Professor at Atomi University in Tokyo, Japan. His other social activities included being a Board Member at Sasakawa India Leprosy Foundation and Board Member at Japan Society of Social Design Studies. Previously, he worked as Program Advisor and Program Director at The Nippon Foundation (Tokyo, Japan); as Director at Sasakawa Peace Foundation USA Inc. (Washington D.C. U.S.A.); Deputy Director of Sasakawa Peace Foundation (Tokyo, Japan); Director of Sasakawa Central Europe Fund (Tokyo, Japan); Convener/Executive Director of the NGO Forum at the Asian Development Bank Inc. (Manila, Philippines). He holds a Ph.D. in Community Development.

In photos: (left) Global Forum women delegates in a huddle, (right) Dr. Arturo Cunanan leading a discussion with a group of participants.

be a special presentation from Dr. Ai Kurosaka, who will talk about the recent victory at the Japanese court for families afflicted by Hansen's disease. Meanwhile, Dr. Marie Lisa Dacanay will analyse how to enhance the sustainability of people's organizations with concrete examples. Dr. Cunanan will discuss the important roles of people's organisations should play at different stage of Hansen's disease services with special focus on public health.

All the different discussions will be facilitated to help the participants shape the messages that they would like to deliver at the ILC. These messages will be compiled and delivered as the Manila Declaration at the International Leprosy Congress to be held on September 11, 2019. Dr. Nanri reminded the delegates to take advantage of the meeting with Mr. Yohei Sasakawa, Chairman of The Nippon Foundation, and WHO Goodwill Ambassador for Leprosy Elimination on September 9. Mr. Sasakawa is one of the first persons to highlight the importance of working with people's organizations.

Finally, Dr. Nanri encouraged everyone to interact and network among the other delegates. He thanked the participants once more and wished them fruitful discussions, while taking advantage of the forum to deepen their friendship and solidarity with colleagues and to enjoy themselves.

In photo: Global Forum participants pose for a group photo during the first day.

THE AFRICAN REGIONAL ASSEMBLY

MR. TESFAYE TADESSE
Managing Director, ENAPAL, Ethiopia

Mr. Tesfaye Tadesse

The African Regional Assembly was held last March 13-14, 2019 in Addis Ababa, Ethiopia with the **Ethiopian National Association of Persons Affected by Leprosy** (ENAPAL) as host organization. The main objective of the African Regional Assembly was to establish the African alliance to maximize an integrated effort to change the life of Persons Affected by Hansen's disease in the region.

> *The African Regional Assembly was the first time that all organizations of persons affected by leprosy in Africa came together to talk about their concerns. Participants to the first African Regional Assembly came from Ghana, Nigeria, Tanzania, Morocco, and Ethiopia.*

Delegates from these countries shared the challenges they face with regard to leprosy:

- ◊ Lack of awareness
- ◊ Lack of or poor attention on disease vis-a-vis HIV and TB
- ◊ Lack of government support for leprosy treatment and service
- ◊ Unavailability of MDT in community health facilities
- ◊ Lack of finances to avail of services for leprosy-related disabilities
- ◊ Limited access to leprosy services at most nearby health facilities
- ◊ Poor physical rehabilitation services

During the regional meeting, each organization presented their organizational challenges, successes, learning experiences, and ways forward. Participants also discussed how to develop alliance and solidarity among Leprosy organizations in Africa.

At the end of the African Regional Assembly, participants were able to establish the African Alliance.

LEPROSY SITUATION IN AFRICA

Africa is the world's second most populous continent. As of May 2019, UN estimated that Africa has some 1.3 billion people, representing 16.64% of the world's population. Forty one percent of the population live in urban areas with the population density at about 111 people /sq. miles. The continent's total land area measured 29,648,481 sq.km. Disability in Africa resulted from a number of factors such as war, communicable diseases, and traffic accident among others. It is the main causes for the rampant poverty, stigma and discrimination. Persons affected with Hansen's disease, in particular, face social, political and economic barriers that adversely affect their basic human rights.

The chairperson and secretary who will work on the framework of the alliance and solidarity procedures were also selected. The participants also agreed to have the same logo and motto for 2020 World Leprosy Day campaign. The SHF took the initiative to develop and share the motto and logo to each region.

THE AFRICAN REGIONAL ASSEMBLY RECOMMENDED:

- Creating a WhatsApp group to facilitate communication and coordination;
- Bringing up the use of the terminology, “Persons AFFECTED by Leprosy”, and the negative effects of the use of this phrase on the persons affected by Hansen's disease to the Global Forum scheduled in Manila in 2019.
- Stating that leprosy issue is a human rights issue.

In photo: Delegates from the African Region

Mr. Tesfaye Tadesse ended his presentation with a reminder from Mr. Sasakawa that “You are the main actors” in eliminating the disease and bringing an end to the stigma and discrimination of peoples affected by the disease.

THE ASIAN REGIONAL ASSEMBLY

MR. FRANCISCO ONDE

Chairman, CLAP Philippines

Mr. Frank Onde

Mr. Francisco Onde, Chairman of the **Coalition of Leprosy Advocates of the Philippines (CLAP)**, welcomed everyone to the Global Forum. The Asian Regional Assembly Organizations of People Affected by Leprosy in Asia-Pacific was held from March 3-6, 2019 at H2O hotel in Manila, Philippines. Among the goals of the assembly was to create an avenue for the participating people's organizations to become a regional network.

He shared that the assembly participants wanted to be a voice that will speak on the urgent concerns of each leprosy patient during the Global Forum and at the International Leprosy Congress (ILC) scheduled in September 2019.

Participants to the assembly came from China, Nepal, Indonesia, Philippines, and Kiribati. They discussed the issues affecting people with leprosy such as human rights, sustainability, public health programs, and the preservation of leprosy history. Asst. Secretary of DOH Dr. Laxamana also graced the March gathering and gave the keynote message. On that occasion, she emphasized that early case detection has always been the key in achieving the target as well as scaling up of interventions to prevent leprosy transmission. Moreover, effective and efficient program implementation rely on four (4) Cs: commitment, cooperation, coordination, and collaboration.

Mr. Francisco Onde then shared the other resource persons who graced the Asian Regional Assembly and their key messages. Dr. Takahiro Nanri emphasized that Sasakawa Health Foundation is just providing the venue but the participants will have to be the one to use the venue and work for the future of their organisations.

Dr. Alice Cruz, UN Special Rapporteur, discussed her role at the United Nations and the work she has done and shared the achievements of Morhan in Brazil and Felehansen in Colombia in their awareness campaigns.

In photo: Delegates from the Philippines during a workgroup session.

Rev. Luis Daniel Pantoja explained the role of religious organisations and government in empowering and ending social stigma and discrimination. Dr. Marie Lisa Dacanay discussed partnerships and sustainability of people's organizations, one of the most common issue among Asia-Pacific groups. Her key message was "in the case of persons affected by leprosy, social enterprise is relevant to sustainability."

Dr. Maria Faina Diola talked to the delegates about networking of organizations specifically on social marketing. Dr. Diola said that "you must have a central idea, which shows your message and you also need to explain your mission through symbols." HANDA of China, an organization that focuses on physical rehabilitation and empowerment of their members related that as part of their inclusive strategy, it has included non-affected people in the governance of its association. CLAP Philippines also shared its best practices on capacity building. One of this was assisting the Philippine government in the early detection and awareness campaigns. The association's main challenge is the geographical barrier. Being an archipelago, members find it difficult to come together and this impacts on the organization's sustainability.

IDEA Nepal, represented by Mr. Dinesh Basnet and Mr. Amar Bahadur Timalsina, explained about their work on empowerment and advocacy. Among their challenges is the presence of discriminatory laws affecting human rights and dignity in Nepal. By law, someone could obtain a divorce if the wife or husband is affected with leprosy. PerMaTa of Indonesia shared that the association has partnered with the Indonesian government in advocacy such as organizing forums and launching educational campaigns. Like CLAP, PerMaTa faces the challenge of working in a big country and an archipelago at that. Observers from Kiribati, an island in pacific, shared that their main challenge is that the people affected with leprosy in their country are not yet organized. They also face more pressing climate issues such as flooding.

Mr. Francisco Onde thanked Inter Press Service (IPS) news agency for their presence during the assembly. He ended with encouraging everyone who would like more details on the Asian Regional Assembly to read the report.

THE LATIN AMERICAN AND CARIBBEAN REGIONAL ASSEMBLY

Mr. Faustino Pinto

MR. FAUSTINO PINTO

Vice National Coordinator, Morhan

The Latin American and Caribbean Regional Assembly had for its theme: **"People in Search of Dignity and the Defence of Human Rights of People Affected by Hansen's Disease"**, Mr. Faustino Pinto shared. It was the first time that organizations of people affected by the disease were given a central role and were able to jointly discuss, reflect, and agree on ways of addressing common issues that included the perspective of people who lived with the disease.

From March 11-14, 2019, the social movement from Brazil, Bolivia, Columbia, Ecuador, Mexico, Paraguay, Peru, USA, Portugal, Germany, and Japan, as well as the representatives of WHO, the Pan-American organizations, The Nippon Foundation and Sasakawa Health Foundation, Felehansen, and the national health councils gathered together to exchange their experiences, discuss the situation of leprosy in their respective countries, and enable those affected with the disease to present their stories.

The meeting centered on the strategies to promote the third pillar of WHO's Global Strategy for Hansen's Disease for 2016-2020, which focuses on the elimination of the discrimination and the inclusion of people affected by Hansen's disease as well as the Principles and Guidelines of the United Nations Human Rights Council.

During the four-day gathering, delegates and their organizations got acquainted with each other. They were welcomed with samba and bossa nova songs. There were also cultural exchange activities that included a visit to the iconic figure of Jesus the Redeemer; the special participation of Mr. Yuri Guerra, a young Brazilian and a Morhan volunteer artist, who lives in Italy; and the launching of the book, "Portrayals of a Public Policy: Memories of Violated Childhoods in Brazil and Portugal by the author, Lilian Angélica da Silva Souza, which tells the stories of children separated from their families due to the segregation policy implemented in relation to those affected by Hansen's disease in the two countries.

Among the most significant outcomes of the first Latin American/Caribbean Regional Assembly on people affected by leprosy was the Creation of the Coalition of the Latin American and Caribbean of Entities of People Affected by Hansen's disease. The coalition agreed to meet every three (3) years with the next meeting scheduled in 2022.

At the opening of the meeting, the Oswaldo Cruz Foundation signed an agreement of technical-scientific cooperation with the Movement for the Reintegration of People Affected by Hansen's Disease (Morhan). The agreement focused on developing public policies to fight against prejudice regarding people affected by Hansen's disease and collaborative strategies to historical preservation, communication and rehabilitation of people affected. The National Observatory of Human Rights and Hansen's Disease was also launched during the regional event. The new body will monitor complaints and violations, actions seeking protection of rights and confrontation of the social conditions that keep Hansen's disease as a problem of public health and human rights in Brazil.

Another highlight of the regional meeting was the adoption of the Coalition to use Hansen's disease or simply Hansen to replace the outdated word "leprosy" as a way to designate the disease and the people affected by it. The gathering also approved the Creation of the of the Latin American and Caribbean Protection Network for Immigrants Affected by Hansen's disease and the extension of the Committee for Assistance to the Brazilian immigrants affected by Hansen's disease to all Latin Americans and Caribbean as well as to other regions. The need to consider issues related to equity, gender race, class and sexual orientation was also agreed in the local, national, and international proposals, Mr. Faustino Pinto added.

In photo: Drafting committee meeting

> ***The results of the three regional assemblies showed that across the different continents delegates share the same hopes of making changes in the lives of people affected with Hansen's disease.***

SOCIAL BUSINESS/ FUNDRAISING/ MANAGEMENT

Empowering People's Organizations Through Social Entrepreneurship

MR. EARL PARRENO

Chairperson, Alter Trade Foundation Inc. (ATFI)

> *Social businesses or social enterprises are "wealth creating organizations with a mission of improving societal well-being. Simply put, these are businesses with social aims."*

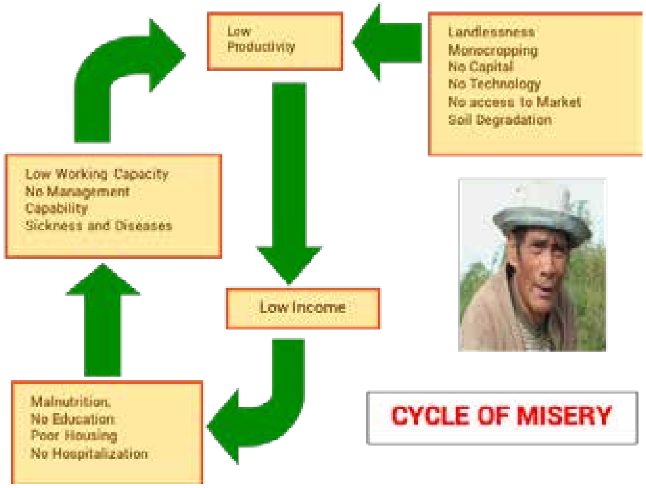
Social enterprises are profit-oriented organizations that aim for the common good and triple bottom lines: financial, social, and ecological. To distinguish a social business/enterprise from any other business, he shared that it should be designed to generate profit, benefit society or community, and uses profit to continue its social mission. He emphasized that the concept of social business is not new as many organisations with a social mission such as poverty reduction have been doing social business since the 1920s.

Mr. Earl Parreno introduced Alter Trade Foundation Inc. (ATFI), a non-stock, non-profit, non-governmental organization established in 1997 to provide support services to marginal producers. It aims to a) develop the capacity of rural marginal producers for them to engage the whole value chain and claim ownership of their respective products; b) help build the pillars of local economy development in area where ATFI have social enterprise engagement towards poverty reduction; and c) establish a socially and ecologically oriented broad consumer base that patronize fair trade products and supports the growth of community-based agricultural production.

Mr. Earl Parreno

More than 40% of Filipinos are in poverty, Mr. Parreno shared. In Negros where ATFI operates, sugar plantation is the main mode of the economy, a lot of people are so poor that they could not even eat one meal a day. Negros is home to about 2.5 million people and 90% of its inhabitants are plantation workers, fisherfolk, small farmers, and industrial workers. Most of the Negros agrarian reform beneficiaries (ARBs) were former farmworkers who earned an average of Php71 a day (or US$1.40) in the former sugarcane plantations called haciendas. Women workers were paid half of what the men received. Child labor was a common practice in the plantations.

He explained that poverty does not only mean a lack of money. He explained this in what he referred to as the Cycle of Misery wherein these landless and monocropping farmers who had no capital, technology, or access to market, and plant on degraded soil produce very little (low productivity), which then results to low income. Low income leads to other social problems like malnutrition, no education, poor housing, and no hospitalization, which then leads to low working



capacity, illness that contribute to low productivity. The cycle is then repeated.

To help the ARBs, ATFI analysed the various problems and matched these with different ATFI support Services. However, at ATFI, they realised that those interventions were not enough to address all the problems. ATFI introduced its Transformational Service Programs that included holistic organizations empowerment, sustainable agriculture technologies, credit and savings program, and advocacy and networking in order to train the ARBs into farm entrepreneurs. In the process of helping the ARBs, ATFI had established several organizations. One of these was the Social Enterprise Empowerment for Rural Development Inc. (SEED, Inc.) to provide training and capacity building for people's organizations and NGOs on social entrepreneurship. The other was the NOFTA Fair Trade Haus, Inc. that aims to link small producers to the fair trade and socially-oriented consumers and enterprises. ATFI's concept of "from gate to plate" is composed of many stakeholders that connects small producers to the market through ecologically and socially-conscious value chain.

As a result, partner farmers' monthly income increased. Farmers planting diversified crops earned Php6,994 while those planting sugarcane received Php7,532 more. As a result, these partner farmers' households became 100% food sufficient. Eighty percent of the families have crossed the poverty line. On the social side, 414 of farmers' households were able to send their children to college. They were able to improved their homes to semi-concrete or concrete and buy home appliances. They do not use child labor in production. There is gender balance in the organization and in production. In the ecological aspect, 623 farmers have conducted Disaster Risk Reduction (DRR) planning and planted 10% of their farms with fruit-bearing trees. These farmers do not use genetically modified crops (GMOs) and insecticides.

Mr. Parreno further shared ATFI's cyclical model in engaging the communities consisted of four main phases: planning, capacity-building, setting-up, and mentoring. Once these communities are ready to scale up, they assist them following the same cycle. For ATFI, three (3) traits characterized an empowered people's organizations: 1) they own the enterprise; 2) they work in the enterprise; and 3) they manage the enterprise.

In photo: Ms. Jayashree Kunju asking a question during an open forum session.

QUESTIONS & SHARING

Some of the key questions raised by participants included the following;

1. Ms. Jayashree Kunju (IDEA, India): Is ATFI an NGO or a business entity? Were these organizations within ATFI registered separately?

Mr. Parreno: ATFI is an NGO engaged in business but its profits are ploughed back to the foundation. NOFTA owns 60% and get 60% of the profits. ATFI has two (2) profit centers: NOFTA trading house and credit facility, which are 2 the sources of income to sustain the organisation.

2. Mr. Matthias Duck (ILEP, Paraguay): more and more people are paying more attention to fair trade products.

Mr. Parreno: In the early years of ATFI, most products—muscovado sugar and Cavendish banana—were exported to France and Germany. Fair trade organizations are growing because of mindful consumers who want to consume products that are sustainably produced or are traceable to the organizations or people who produced these products. Muscovado used to be known as the poor man's sugar. A German partner gave them capital to turn muscovado into organic sugar. Thus, the market grew but for the first 17 years, ATFI was the only one producing organic sugar for the supermarkets. Fair trade products are still not as big in the Philippines but organic products are becoming a norm.

3. Ms. Lilibeth Evarestus (IDEA Nigeria) wanted to know more about ATFI's credit and access savings program so she can take it home and empower women in Nigeria.

Mr. Parreno: ATFI started its credit and savings program with a capital of Php8 million. For the credit program, there's a need to schedule the program. The release of money corresponds to the scheduled work and only the needed amount of money was released to ensure that the loan will be used for business and not for family consumption. There is also a need to explain the setting of interest rates and to teach financial management to the members. Most of the recipients did not go to school thus, it is important to teach simple "money in and money out". Strictly supervised is the best description of program.

4. Mr. Michael Chen (HANDA, China) expressed his interest in the sharing. He's interested to learn about social enterprise and that it has triple bottom line. He inquired to whom the foundation belongs and if the ATFI is making profits. He asked Mr. Parreno if he has experience on social enterprises that failed and the cause of failure given that there are a lot of social enterprises that do not succeed.

Mr. Parreno: ATFI is a social enterprise in itself and develop social enterprises at the PO level. The 13 primary associations have their own enterprises, which earn from sugar cane production, diversification of crops sold through the trade houses, and from their own credit program offered to other sugar cane planters. For the foundation to be sustainable, it has its own credit program and through NOFTA trade house. Profits from these two sources are not enough. Hence, ATFI tries to raise funds from donors.

On the 2nd question, Mr. Parreno explained that not everyone can become businessmen. There have been several failures. Three main reasons why businesses fail include: (i) Mismanagement. An organization that grows and earn millions tend to mismanage finances; (ii) Mission drift. Organizations go into business to uplift the welfare of their members, but after the organization grows, it becomes personal. (iii) Regulatory environment. Local officials or leaders of organizations put restrictions on their operations and this is where corruption comes in (when getting license, permissions, too many red tape or bureaucratic processes, etc.). There are 30,000 considered social enterprises but only 30% have succeeded or 90% are successful.

5. Mr. Paulus Manek (PerMata, Indonesia): How much capital come from people with disability organization, challenge of development, and if ATFI involve people with Hansen's disease?

Mr. Parreno: When ATFI started, it only had Php50,000 capital. The first shipment of sugar was a failure. It was very dirty, unhygienic and the bananas were all rotten. Farmers did not know how to harvest, when to pack, etc.. But their market was a solidarity market, consumers paid for them even if they could not use the products for two (2) years until they succeeded in bringing products to the market that meet quality standards which involved fair trade inspections, etc. There's a need to discuss not only capital but partner requirements. Business had a lot of trials too like market, production processes, capital and solidarity markets. Sasakawa Health Foundation could provide solidarity market initially.

Mr. Manek further noted that one thing is to hear the presentation and catch a lesson, more important is to see the practice. He asked if ATFI could invite them to see the practice and asked if it has teaching materials since their members are farmers who are illiterate. Mr. Parreno replied that it would be ATFI's pleasure to invite Mr. Manek's group. He explained that the inputs come from the business schools but it is always challenging to explain such to farmers who didn't go to school but there are ways of doing that. He shared the Latin American invention: education for the people. One of this is making terminologies simple or understandable to the listeners.

6. Dr. Cunanan congratulated the speaker for its best practices on sustaining social enterprises for the last 25 years. He asked how social enterprises can consider social marketing when products are produced by stigmatized people? Previously, they wanted to produce ice cream in an island known to be a leprosy island. Also, POs engaged with people with Hansen's disease find it difficult to find capital. A starting point is needed. We all need nurturing in terms of grants, capacities, because of the high rate of failure. He emphasized that it is important to consider how SE empowerment could lead to the removal of stigmatization by providing social upliftment to the people.

Mr. Parreno shared that one of the social impacts is increased self-esteem. When someone already has an income the person or the family is no longer discriminated in society or in the family.

GROUPWORK

Workshop Questions:

1. What product or service can your organization develop or produce?
2. Where will you market the product or service? Who are your target customers? Can it create profit? How?
3. What are the things you need to develop the service or product? Do you need a building, machines, etc.? Where do you plan to get the funds to start your business?

SUMMARY OF GROUP SHARING

PRODUCTS OR SERVICES

The products identified by the different groups included virgin coconut oil, woodcraft (toys/ educational materials, baskets, flower stand/ statues, wooden stands), papercraft (office files, photo albums), leather items (belts, bags, etc.), tailoring and weaving, coffee roasting and grinding, housing repair services/low cost housing, and embroidery and cushioning, rugs, honey, mushroom, catering, day care center, and other products (washing powder, incense sticks, savouries). Members from Bangladesh, DR Congo who formed one group chose agriculture, livestock, carpentry, sewing/tailoring, carpenters, soap making and production of assistive devices as their products. Another group (mainly from Brazil and Colombia) interestingly identified social capital, education, social justice, citizenship, and human rights and advocacy as their products.

TARGET MARKET AND PROFITABILITY

Almost all the groups with specific products think that their products are profitable. Five (5) of the groups identified the local market as a starting point especially within their organization and entering the international market later on. One group talked about selling their products online while still focusing on the local market. One group (4) thinks the government is their main market.

BUSINESS DEVELOPMENT NEEDS

The common business development need identified by the groups is capability building in the areas of marketing and business management and capital fund. Other needs included technology, raw materials, equipment, facilities. For funding needs, the group identified a broad source of funds including microfinance, banks, credit and savings program, the government, international organizations, and other stakeholders. Group 7 (Philippines, India, China) thought that for their catering and rental services, 50% down payment from their customers are also sources of funds.

COMMENTS FROM MR. PARRENO

Mr. Parreno commented that the products and services need to be specific. These products should generate revenue for the social enterprise, and needs to cope with the changing times especially for handicrafts. Further, he also emphasized the need to do business planning and more importantly, to continuously assess the customers' changing wants and not only on their needs to ensure that these are addressed. He noted that Group 4's concept of profit in the form of human capital is very unconventional.

Dr. Nanri commented that the workshop is very inspiring and that it was a good brainstorming for each organisation. He also noted the need for a more comprehensive approach for social business. He also observed the need for training on what is social business and the need to come up with business planning and business implementation. He shared that it is one of the things he is teaching in the university. He thinks that targeting private foundations and governments is very old-fashioned and not sustainable. There is a need, he said, to look for new funding sources such as international corporations, microfinance, crowd funding, etc. as well as new partnerships, with universities for instance. He further shared that his university has connections with international corporations and NGOs.

In photo: Ms. Jennifer Quimno of CLAP with some Philippine participants during a workshop.

NETWORKING & VOLUNTEERS

Network Volunteer Experiences and Use of Accessible Technologies

MR. ARTUR CUSTODIO
MR. FAUSTINO PINTO
Morhan, Brazil
with Ms. Sheila Esper (translator)

Mr. Artur Moreira Custodio

Mr. Artur Custodio started the workshop with an activity, where each person from each table was asked to hold a part of a string. He used this to illustrate what a network is and continued to share Morhan's experience on networking and use of accessible technologies. He showed a map of Brazil which shows the different color-coded points to signify the number of volunteers in each area. With the use of the map, Morhan is able to know the monitor the size of the organization.They have about 1,000 volunteers deployed each day. However, there are areas with high incidence of Hansen's disease but with few volunteers. He further shared that the map could be constructed with Google technology and is helping them do their work better.

He presented networks as metacentre organization forms with multiple nodes. He described the nodes as places of joints on which impulse set is not in a fixed place and likened the nodes to the tables where the people holding the string are located. Nodes can be people, groups, and entities. Networks are proposals for collective work, a contribution to a new way of articulating health transformation to different people. He shared that networks can be local, national, regional and transnational with common objectives.

Mr. Artur Custodio further shared that Morhan is composed of volunteers and stakeholders. He introduced the volunteers who are with him. One is a professional translator and another is an anthropologist. Both are helping Morhan with the translation from Spanish to English. He shared that each one of the volunteers does what they do best.

In terms of communication and training, Mr. Artur Custodio shared that Morhan had to think of the best ways to communicate within their organization. They had to look at the big picture. Considering the many volunteers, they get the key volunteers to train other volunteers. Some of the volunteers are famous artists in Brazil. One of them is an artist who can talk about Hansen's disease in his show.

He also shared that not all of them know all the volunteers. They created this database through Google, which is accessible in any computer, where volunteers can add their information. If someone comes to them with a legal problem, they can look in the database for the appropriate volunteer who has a law expertise. They also used to have a hotline where anyone can learn about Hansen's disease. Today, they have the TeleHansen. They are also using other platforms like Facebook which reached almost 9,000 people They also asked You Tube and negotiated for free use of the media for a certain number of viewership.

QUESTIONS & SHARING

The following are the questions raised after the presentation and Mr. Artur Custodio's responses:

1. Ms. Jayashree Kunju (IDEA India) wanted to know how many people Morhan has reached. She explained that in India, people treated from Hansen's disease are removed from the registry. This created a huge data gap on Hansen's disease cases.

Mr. Artur Custodio replied that he has no idea as of now and that Morhan is working on improving the map. He also shared that in Brazil, there is no problem with the registry. Morhan pressed the government and it improved its services. The Brazilian government knows how many people has this disease but do not know how to cure the disease. There is a need to collect post-treatment data.

2. Mr. Amar Timalsina (IDEA Nepal) asked how Morhan attracted people to become a volunteer and asked if one of the volunteers can share their experience on what motivated them to become a volunteer considering that in Nepal, nobody wants to be part of an organization involved in leprosy because of the stigma. Dr. Michael Chen (HANDA, China) commented that "it is easy to attract people but maintaining them is difficult". He asked how Morhan motivates and keep the volunteers. He also asked a volunteer to share what keeps him/her working with Morhan and if they receive any benefit.

Mr. Artur Custodio replied that people's organizations do all the work. Morhan have people affected by Hansen's disease and those who were not affected. Those affected who joined Morhan were rehabilitated. He added that they need all kinds of people and they need to listen carefully to the people. The people who are mobilized need to see the people affected by Hansen's disease. He added that it is easy to attract the people to join but maintaining the people is very difficult. As an example, he mentioned Glousa, an anthropologist who came to Morhan. She asked if she can do a documentary of the children separated from their parents, which Morhan allowed. He explained that one of the things that Morhan believes can help maintain people is letting them decide how they can contribute and what will make them happy in working with the organization.

A Morhan volunteer shared that she is new in the organization and loves to fight against the discrimination and to bring people together. She liked the idea that Morhan, which was born in democracy, the same time the dictatorship ended in the 1980s, has kept alive the spirit of democracy in the organization and the fight for related policies. How they engage with different networks is very amazing. These are what keeps her in Morhan.

In photo: Mr. Amar Timalsina asking a question during the open forum

3. Ms. Ermawati (PerMaTa Indonesia) asked about the professional levels of the volunteers and if the volunteer tasks were related to their profession. She further inquired if there is a termination time and code of conduct for the volunteers.

Mr. Artur Custodio replied that Morhan conducts business differently depending on the region. They have all kinds of volunteers who know how they can contribute to the region. The needs are matched with the available volunteers who can do the task. In ACRI region, they created a new unit to give education inside Morhan. They received grants for people affected by Hansen's disease to go to university and they return to them. Long-distance training courses are also done and they have a network of lawyers who think about the best solution for a certain problem. Morhan engage volunteers in different ways.

4. Mr. Amar Timalsina (IDEA Nepal) asked how they can have volunteers like Morhan and if there are provisions to become volunteer.

Mr. Artur Custodio explained that to establish a network, there is a need to form groups who understand what they are doing. He added that this is what will be done in the next activity and emphasized that planting the seed to grow all the networks around the world is important. He stressed the need to be very strategic and united.

5. Mr. Kofi Nyarko (IDEA Ghana) posed a question: Am I here to fight discrimination against leprosy? He emphasized the need to fight the stigma against Hansen's disease and stressed the need for inclusive advocacy to change public views on Hansen's disease. He added that the use of leper colony and leprosy hospitals should be stopped since these are creating an impression that leprosy is incurable.

Mr. Artur Custodio replied that the network has the role of sharing their personal experience so they can start to change something. Fighting the stigma is one of the main axis of the movement because Hansen's disease stigma is ancient. It is within the culture and it is a structural stigma.

WORKSHOP

Workshop questions:

1. How can I use the concept of network in my organization?
2. How can we create a worldwide network of affected people by Hansen's disease?
3. Which are the aims of a worldwide network (give two at least) and explain.

SUMMARY OF WORKSHOP RESULTS

USE OF NETWORK

The different groups thought that the concept of network is very useful within the organization to promote internal communication, promote and create partnerships, and raise awareness on Hansen's disease to the general public. In the case of the Philippines and Indonesia, networks are very important because these two countries are archipelagic. Networks save time, effort, and resources.

HOW TO CREATE A WORLDWIDE NETWORK

The responses across the different groups are very similar. The global network of people affected by Hansen's disease can be established through social media, conferences and meetings. Social media tools mentioned included Facebook and WhatsApp. Most of the groups think that conferences and meetings are also good avenues for establishing a worldwide network.

OBJECTIVES OF THE WORLDWIDE NETWORK

The different groups identified several objectives that a worldwide network should aim for. Among these were: a) To facilitate sharing of ideas, experiences, and best practices; b) To unite voices from various countries to create bigger political influence to make policy changes; c) To unify understanding of issues; d) To set common goals and targets; e) To provide mutual support to all countries; and f) To provide visibility to what the group is already doing.

COMMENTS FROM MR. ARTUR CUSTODIO

Mr. Artur Custodio thought all the results of discussions presented were wonderful. There were differences in words used but the ideas were very similar. He explained that the principle of networking is respect for the different ideas, cultures, and languages among others. The other principle is good communication. All the groups have the same idea that the network is very important.

In photo: Participants of the Global Forum holding a part of a string during the Networking & Volunteers session of Mr. Artur Custodio

He observed that some ideas appear to solidify the concept of network. Benefits, exchanges, sustainability, economy of time, resources, resource mobilization, a stronger voice, in other words, create parallel networks to deal with the government, universities, and other professionals. Everything aims to impact this whole cause. The future steps can be planned like creation of common programs, logo, website including international campaign. In terms of rules, respect for language, culture, and ideas should prevail to bring other groups to the network. He encouraged everyone to make the meeting a first step to a very powerful network.

Dr. Arturo Cunanan congratulated Morhan's networking system. He asked if the group can use network as a noun or as a verb. Like, forming a network to network. He added that he hopes that concrete actions for putting up a network will be done before the meeting is finished. Dr. Michael Chen of HANDA, China added that while the group understands that network is very important, there is already a global network in the room like IDEA Nepal or IDEA India which are already operating in various countries. He suggested starting with these as a base for the global network.

Mr. Mathias Duck concurred that there is the WhatsApp group called Global Leprosy Champions, a network of people affected by Hansen's disease. He added that the group needs to see how to make it work. But everyone agreed about moving forward in putting up such a global network.

Ms. Glaucia Cristina from Brazil, a volunteer in Morhan for 10 years shared that she was affected with Hansen's disease including her two-year old kid and 23-year old daughter. That was what brought them to Morhan. She said all the people affected by Hansen's disease need them and shared about her women's group from Morhan. They created a WhatsApp group to communicate, which was initially composed of 10 people. They do not know each other but they had an idea after the first meeting with Morhan. She went to Morhan with a compromise to become the leader of women affected by Hansen's disease. She continued to share that they got their lives back in their hands afterwards and implored the women in the room regardless of which state or country they came from to help women affected by Hansen's disease.

Mr. Artur Custodio shared that Ms. Glaucia Cristina moved Morhan to reflect and change. Majority of the people in Morhan are women but majority of the board are men. Since last year, 50% of the board members are now women. He added that their network needs to work with another network that suffers from stigma. Women with Hansen's disease and who are poor suffer from stigma more than men who have Hansen's disease but are rich. They enjoined everybody to help construct the network in the coming days.

Ms. Jayashree Kunju of India shared that people, especially women, do not feel safe sharing intimate things. She recounted her experience wherein one of the members brought up her fears to the group. They thought about making the support group formal and of appointing leaders but also considered the possibility that power will be held by only a few people. She emphasized what can be achieved by self-help groups (SHG). She said she also supports the idea of a global leprosy champion group.

Ms. Jennifer Quimco summarized the discussions and exchange of ideas of the second workshop. The group decided that a network for the group will be created. Everyone was glad and agreed to the formation of a network, which will be led by Mr. Artur Custodio.

Hansen's Disease and Human Rights

DR. ALICE CRUZ

UN Special Rapporteur on the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members

Dr. Alice Cruz

Dr. Alice Cruz expressed her gratitude to the Sasakawa Health Foundation (SHF) for the opportunity to speak at the Global Forum. She encouraged the delegates to ask questions and stressed that it was more important for her to listen to what they want to say. Although she knows that it will be part of the discussion at the Global Forum, she will stick with the term Hansen's disease.

A Human Rights Approach

Dr. Cruz began her address with a reference to the Sustainable Development Goals (SDG) of the United Nations, which is about development with no one left behind. However, the reality is, in many parts of the world, many people affected by Hansen's disease are being left behind. **"It is our job not to leave anyone behind,"** she declared. Based on the Human Rights Framework for Action, the main features of human rights are universality, indivisibility, participation, accountability, transparency, and non-discrimination. **"These should be our goals,"** Dr. Cruz stated that this should be the mission of representatives of people with no voices. She then explained that human rights can be an important instrument and strategy in the struggle of persons affected by Hansen's disease.

> *"For persons affected by Hansen's disease, the first step to human rights is to achieve the rights to claim rights."*

Human rights is **"when people stand up and claim for their rights by themselves. We need to do this together with regard to Hansen's disease,"** Dr. Cruz stated. Governments are bound by their obligations to protect, promote, and fulfil the human rights of their people. All people without any exception have the right to a dignified life, not to be discriminated and to be treated as equals. In different places, human dignity

DR. ALICE CRUZ is an external professor at the Law School of the University of Bolivar, Ecuador. Her doctoral work focused on the various social dimensions of leprosy and identified the countries where leprosy is a neglected disease and the countries where it is an important and rare disease. She had studied the different barriers to access early diagnosis and to find quality care by persons affected by the disease as well as the social, economic, familiar and personal life conditions of people afflicted by leprosy. She has worked with Brazilian nonprofit organizations such as the Brazilian Movement for the Reintegration of People Affected by Hansen's Disease (or Morhan) where she was involved in the international symposium on human rights, participated in drafIng the WHO Guidelines on persons affected by Hansen's disease. She served as a member of the international association council and has conducted fieldworks in Portugal, Brazil, and Africa. She has written on leprosy and the stigma attached to it. She has engaged with various stakeholders: public health professionals, medical doctors, civil society and persons affected by Hansen's disease.

mean differently in different regions. Even so, she stressed, **there is "no dignity, no discrimination, and no equality, if there is no right to self-determination."** This should be our common goal: that persons affected by Hansen's disease have the possibility of being their own representatives, people speaking with their own voices, and claiming their own rights on their own terms.

Segregation Policies

Hansen's disease is a human rights issue, Dr. Cruz declared. Throughout leprosy's first modern history there were many human rights violation committed against persons affected by Hansen's disease and their families. From 1873-1948, the government with the assistance of medicine had perpetrated massive and large-scale human rights violation. In 1879, the governments decided that the only way to stop the disease was to segregate persons affected although there was no scientific evidence to support this belief. In 1923, a similar policy to segregate children of persons affected was enforced. In 1924, Hansen's disease experts asked the UN to prevent persons affected by Hansen's disease from circulating within countries and to other countries.

Even if these policies were officially abandoned in 1948, the effects of these polices lasted until the late 20th century. Persons affected by Hansen's disease continued to be discriminated because of institutional stigma. Therefore, stigma is also a product of state policies. This is a crime against humanity since these policies were directed against a group of people, Dr. Cruz repeated. Thus, persons who suffered from these laws and their children have the right to reparation measures. She congratulated Japan for being the first country in the world to recognize the rights of persons affected by Hansen's disease and their families who suffered crimes against humanity.

Dr. Cruz also discussed the existence of forced colonies, which existed not only in Europe but all over the world. Families suffered and this created a human rights violation that have consequences in the present. **"We cannot detach the past from the present,"** she stated. **"We cannot separate those who suffered from those already being treated of Hansen's disease since they are interrelated."**

Policymakers do not really know what is going on, Dr. Cruz disclosed. Based on her consultations with persons affected by Hansen's disease, with NGOs, and member states, many people affected by Hansen's disease still suffer informally from the stigma from within their families, at their jobs, schools, etc. Harmful stereotypes that support discrimination remain alive. These can be traced to traditional or religious views and to ideas created by medicine (e.g. Hansen's disease is highly contagious). Women and children are more vulnerable and many experience abuses in different settings based on the testimonies she received. The data shows that people who are in these vulnerable positions experience higher stigma and discrimination. They suffered all sorts of violence: physical, mental, sexual, etc. It was very disturbing that women affected by Hansen's disease experience a lot of physical and sexual violence. Hence, it is important not to treat Hansen's disease homogenously.

> "*Today's governments are accountable for the ongoing stigma and discrimination against persons affected by Hansen's disease and their families.*"

Stigma and Discrimination

Discrimination exists at all levels. At the macro-level of global health, medicines for treating Hansen's disease and its complications are still not where they should be. At the level of the state, discriminatory laws remain. There is also institutional negligence since persons affected by Hansen's disease are not acknowledged by most state policies. Most countries do not have reparations measures for official segregation. These reparation measures are important since they also educate the way people look at those with Hansen's disease and this is evident in countries that have adopted reparation measures like Japan and Brazil. At the level of social life, pervasive harmful stereotypes continue. The consultation made her realize that persons affected by Hansen's disease are still far from meaningful participation in health services and in policymaking at the community level.

Some of them think that suicide is the only way to end their suffering. "This is the most extreme form of dehumanization that humans can suffer," Dr. Cruz added. If persons are denied dignity, then they see their right to life as jeopardised. When it comes to human rights, one must talk not only about the right to health but also of cultural rights,and all other rights. People die when they are denied the right to a dignified life as evident in the cases of women who suffered all types of violence. There is a need to make our speeches, our voices stronger and more powerful because "stigma kills".

> *It is also important to address the psychological and mental well-being of persons affected by Hansen's disease since they experience many mental disorders due to stigma and discrimination.*

The Human Rights Approach

Approaches to dealing with Hansen's disease cannot be a charity nor a health approach. These two approaches are not about human rights since it is about autonomy. It is about the right to citizenship; the right to have our own voices, the right to our own places, and the right to represent ourselves. That is human rights, Dr. Cruz declared.

In 2010, many stakeholders realized that medical treatment of Hansen's disease was not enough to remove the stigma. The Nippon Foundation (TNF) fought for the recognition of the human rights of persons affected by Hansen's disease, which led to the development of an important human rights instrument. The UN General Assembly (GA) adopted Resolution 65/215 accompanied by the Principles and Guidelines on the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members. Although a big achievement, having an instrument is not enough since governments do not automatically implement it. In June 2017, the Human Rights Council adopted Resolution 35/9, which established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. It is a mechanism that could act quickly to help governments implement the instruments.

Dr. Cruz went on to discuss her present challenges and the main accomplishments in relation to Hansen's disease. A continuing challenge is the difficulty of convincing people, even at the UN level, that Hansen's disease is a human rights issue. Health and human rights are interrelated. People affected by Hansen's disease suffer all types of abuses and violence: physical, mental, sexual as well as denial of access to jobs and to education. All these constitutes a denial of human rights. The bulk of her work consists of consultation and cooperation with the grassroots organizations of persons affected by Hansen's disease. The rapporteurs' work is to listen to people, to their problems, and to persuade the governments to take action. Governments still think of Hansen's disease as something of the past and existing in only a few countries. One important technique, she said, is official country visits but it is difficult to be invited. Governments usually say they are about to eliminate the disease. Dr. Cruz clarified that the matter is not simply about eliminating a public health issue but of access to rights.

Dr. Cruz said the expected outcomes of the mandate is self-determination, which is to allow persons affected by Hansen's disease and their families to speak with their own voices. In June 2019, when she presented her report at the UN, with the support of SHF, ILEP, and the governments of Japan, Brazil, India, Portugal, and Ecuador made a side event for persons affected by Hansen's disease to speak to governments and civil society organizations in Geneva. The movement achieved an important step through Rachna and Faustino's presentation. As a result, in Geneva, people do not speak about leprosy anymore but refer to it as Hansen's disease.

Human Rights Instruments

Dr. Cruz then enumerated some of the international human rights instruments that exist. These could be applied to persons affected by Hansen's disease. Governments are bound by these conventions: the Universal Declaration of Human Rights; the Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the elimination of All Forms of Discrimination Against Women; the International Covenant on Civil & Political Rights; the International Covenant on Economic, Social and Cultural Rights; the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; the Convention on the Rights of the Child; the Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; and the Convention on the Rights of Persons with Disabilities.

Before these instruments could be used, one must check if the countries have endorsed them. Governments are bound to implement these instruments once endorsed. Although the Principles and Guidelines are not binding, Dr. Cruz said they could be related to the other instruments to make a powerful stand. For instance, the provision on persons affected by Hansen's disease and their families have the right to be actively involved in decision-making processes regarding policies and programs that directly affect their lives. This could be linked to the provisions under the Convention on Rights of Persons with Disabilities, which are more detailed. Governments are obliged to provide the conditions for people to participate and to remove social and physical barriers. She added that regional mechanisms also exist but some may not be present in Asia.

Dr. Cruz then explained the different UN human rights mechanisms such as the Universal Periodic Review and the Treaty Bodies. Both are legally binding but slower. Special Procedures are where special mandates are located. Capacity building is needed to understand how these mechanisms work and how to use them. People's organizations should have funds for capacity building. From her experience, the most important human rights mechanism is the organizations' work at the grassroots level because this is where change really happens, she said.

Before ending, she explained some of the good practices for eliminating discrimination. For the state's health sector to take care of delivery of care and awareness-raising activities. For CSOs to be engage in community-based rehabilitation; formation of associative, self-help and self-care groups of persons affected by leprosy; peer counseling at the community level; income generation and education opportunities. She cited two very good practices. In India, strategic litigation—going to justice and demanding rights—is slowly attaining the abolishment of all discriminatory laws. In Brazil, Morhan with the Public Defender's Office created an Observatory on discrimination. She pointed out the importance of having a body to develop mechanisms to monitor discrimination and receive complaints. There is a need to interchange all these experiences.

> *People affected by Hansen's disease suffer all types of abuses and violence: physical, mental, sexual as well as denial of access to jobs and to education.*

Dr. Cruz said she is working on a policy model for the elimination of discrimination against persons affected by Hansen's disease and their family members. She has convinced member states that discrimination endures. She hoped to include the participants' voices in her next thematic report to the UN and provide evidence that discrimination continues. She said she would endorse what the delegates would be recommending in relation to the following:

- The role of of language for the elimination of stigma and discrimination.
- The impact of stigma on family members of persons affected by Hansen's disease
- Policy model for eliminating discrimination and enforcing human rights of persons affected by Hansen's disease and family members

Finally, she thanked Rachna and Faustino for speaking with the UN Deputy High Commissioner for Human Rights Ms. Kate Gilmore in Geneva, who received them in her office. Ms. Gilmore has been engaged in Hansen's disease and encouraged them with these words, "This is your home. This is what we must accomplish: Self-determination. You representing yourself, you speaking with your own voices."

In photo: Ms. Jayashree Kunju of India leading a discussion during one of the workshops

WORKSHOP

Topics for group discussion:

1. The role of of language for the elimination of stigma and discrimination.
2. The impact of stigma on family members of persons affected by Hansen's disease
3. Policy model for eliminating discrimination and enforcing human rights of persons affected by Hansen's disease and family members

SUMMARY OF WORKSHOP RESULTS

GROUP 1

1. Terminology and self-identification. All key stakeholders should propagate the term "Hansen's disease" for self-identification to enable everyone to be familiar with it. Although the term will generate questions because most people are familiar with the word leprosy, after some time, people will get to know about it.

2. Guidelines for communication. The group strongly do not want images on air of deformed fingers, etc. not to use derogatory images to identify us. We also need government to communicate the word that Hansen's disease is curable and early detection could prevent disabilities. Once they are totally cured, the people should no longer be identified with the disease. It would be preferable for celebrities to communicate something about Hansen's disease to the general public.

3. Role of key players and stakeholders. To operationalize the change in term, all stakeholders should use the term "Hansen's disease" at all levels and teach communities to be familiar with the term. They should also use the UN human rights mechanisms.

B. The impact of stigma on family members of persons affected by Hansen's disease

1. Former Hansen's disease's colonies today (land rights; preservation of history; access to basic needs);
2. Past violations and reparation measures;
3. Intrafamily stigmatization and violence (does it exists? Who is mostly affected? How to tackle it?);
4. What should be the role of key players and stakeholders (Governments; International Organizations including OHCHR and WHO; NGOs; Legislators, Academic Institutions; People's Organizations, etc.).

In photos: (left) Ms. Sheila Esper translating for Mr. Artur Custodio, (right) African group presenting workgroup results.

GROUP 2

1. Former Hansen's disease's colonies today
    - ◊ There are only few colonies left today.
    - ◊ People in the colonies have land rights. Those remaining have no land rights.
    - ◊ Some countries like China, India, and Philippines have museums. Others do not have.
    - ◊ Recommendation: Government should provide land rights to the people since they have been there for many years. Government should also give them access to basic needs such as water, electricity, toilets, social rights, health, food, education, etc.

2. Past violations and reparation measures
    - ◊ Stigma, discrimination, boycotted, isolation, divorce, abuse and violence
    - ◊ No land rights and no education,
    - ◊ Recommendation: For the government to re-establish all above rights of persons affected by Hansen's disease

3. Intrafamily stigmatization and violence: yes, this exists. Women and children suffer the most. Promote awareness

4. What should be the role of key players and stakeholders
    - ◊ Abolish all discriminatory laws
    - ◊ Provide the people with land rights
    - ◊ Provide political support in all moments
    - ◊ People's organizations should have strong voice and be involved in policymaking at all levels
    - ◊ Office of the High Commissioner on Human Rights (OHCHR) and WHO should push the government to implement the principles and guidelines and to monito the implementation
    - ◊ Communication at all levels at the high-level mechanisms

C. Policy model for eliminating discrimination and enforcing human rights of persons affected by Hansen's disease and family members

1. Implementation of the P&G: identifying priority areas for policymaking;
2. Implementation of the P&G: identifying already implemented good practices on priority areas;
3. Implementation of the P&G: general recommendations and guidelines for policymakers;
4. Implementation of the core values of the P&G by the national Hansen's disease's programs disease: what should be the WHO's goals for ending discrimination?
5. What should be the role of key players and stakeholders (Governments; International Organizations including OHCHR and WHO; NGOs; Legislators, Academic Institutions; People's Organizations, etc.

GROUP 3

1. Priority areas for policymaking:
   Our priority areas are as follows: Women: mothers, housekeepers, sex workers, groups living in vulnerable conditions such as prisoners, people living in the streets, and those in poor living conditions.

2. Are there any discriminatory laws and what we can do?
   Implementation: It is important to distinguish between law in books and law in action. In Brazil, there are no discriminatory laws but in action people suffer. There is also a need to research on laws that can protect people affected by Hansen's disease and for people affected to know how to make use of these laws to protect them.

3. General recommendation: For public campaign to pass on knowledge about these laws to everybody and to empower the persons affected by Hansen's disease and ex-patients about the laws.

4. Role of key players and stakeholders:
   The government to create, modify and execute the anti-discriminatory and reparation laws. We need to have public policies and ban discriminatory laws. NGOs have to propose how to modify these laws on paper and demand to put these laws in practice in the field.

GROUP 4
Priority Areas for Policymaking - Adequate Standard of Living

1. Policy to ensure adequate, fully-trained human resources to give care and treatment. Promoting persons affected and family members wellbeing, including access to the highest attainable standard of health.

2. Policy to ensure that capacity building is provided for persons affected by Hansen's disease including training, access to microfinance, employment and market is made available. Governments need to work on reducing poverty and promoting an inclusive economy.

3. Inclusion of education about Hansen's disease from primary schooling. Tackling gaps in education of persons affected and promoting an enabling educational environment

4. Access to physical space in line with attitudinal changes (housing strategies and access to public space). This is to facilitate the day to day living of persons with disabilities.

5. There should be sufficient research funds for tools and equipment to make life of easier for persons with Hansen's disease.

Priority Areas

1. EQUALITY AND NON-DISCRIMINATION IN RESOURCE DISTRIBUTION
   - Institutional recognition of persons affected and their family members rights
   - Access to basic services and infrastructure
   - Empowerment of vulnerable groups (women, children and persons with disabilities)

2. ADEQUATE STANDARD OF LIVING
   - Promoting persons affected and family members wellbeing, including access to the highest attainable standard of health
   - Reducing poverty and promoting an inclusive economy
   - Tackling gaps in education of persons affected and promoting an enabling educational environment
   - Housing strategies and access to public space

3. PARTICIPATION
   - Promotion of inclusive governance
   - Enabling political participation, transparency and accountability
   - Structural inequalities that prevent persons affected to achieve active, free and meaningful participation

4. POLICIES OF MEMORY AND RAISING AWARENESS
Policies on memory and reparation measures

GROUP 5
Participation

1. In terms of promotion of inclusive governance
   - People affected by Hansen's disease need to be organized and governments need to support these organizations.
   - Access to education and capacity building
   - Knowledge about rights and entitlements

2. Advocate with the government
   - People affected by Hansen's disease need to be unified
   - Organizations need to be part of the decision-making process

3. Structural inequalities that prevent participation
   - Lack of educational opportunities
   - Low self-esteem
   - Stigma/fear
   - Limited knowledge about human rights system
   - Limited access to justice
   - Government inaction

COMMENTS FROM DR. ALICE CRUZ

Dr. Cruz thanked everyone for their work and for giving clear and concrete recommendations. She pointed out, however, that this was just the start of the discussions. She promised to get back to the delegates through consultation. She then presented the policy model (see box) for her next thematic report to the UN.

Dr. Cunanan interposed and reminded everyone that the workshop should generate recommendations that will be presented to the International Leprosy Congress (ILC). He believed it would be good if the discussions are brought up in a plenary and everyone can comment on the issues. Those issues should have been deliberated

Key Ideas of Special Rapporteur's Thematic Report to the UN

1. Human rights change the way Governments interact with people
2. Human rights help to identify gaps and structural weaknesses
3. Human rights clarify decision-making and accountability
4. Human rights have primacy over other laws and provide a framework for governance and all decision-making

in the plenary and the recommendations included in the manifesto. There are also other issues and the whole context on human rights and inclusion are well taken. From the various issues discussed, the group needs to focus on specific issues that could be acted upon. There is also a need to hear the opinions of the other groups in order to come up with holistic output.

Dr. Cruz concurred with Dr. Cunanan which was why she said the discussion is only beginning. There are not enough people for the collective discussion on some of the recommendations such as using the term Hansen's disease. Her attention was drawn to the issues of what happens when a person gets cured of the disease in terms of self-identification. Many formerly afflicted with the disease do not want to be associated with Hansen's disease afterwards. She said governments need to provide protection to these people. They need special measures. If we are to demand for rights, however, a strong identification process is required. Self-identification is important in order to claim rights. If one cannot identify with something, one cannot claim rights. Another critical issue raised by all the groups is awareness raising. However, no significant results have been achieved in this area, which points to the need to engage communication experts.

Ms. Jayashree Kunju raised the usefulness of having big funds for information and educational campaigns (IEC) that are ineffective. She pointed out that people live in isolated worlds: one world and the rest of the world. There is the world of people with leprosy, the world of people's organizations, and the others. People with leprosy are not portrayed in normal situations such as sitting in a café having coffee with other people. There are no visual images of real human beings. She said a lot of people in her country continue to think that there is no leprosy. Even doctors are bewildered that there is leprosy. She admitted not knowing how to go about communicating this important point but stressed the need to reach a critical mass in order to get the message across. Dr. Cruz assented to this. "Persons affected by Hansen's disease have to be at the forefront of the battle. They are the same as everyone else." She emphasized the importance of communicating this point so that society recognizes that people with Hansen's disease are the same as anyone else and does the same things.

Mr. Artur Custodio of Brazil brought up two (2) issues: the meetings and terminology. First, he said the group is not starting from zero since there have been local meetings and regional meetings about certain issues that were also discussed with other organizations. The Global Forum is another occasion where these same issues are being raised but which have been agreed upon in the regional meetings. All these need to be put together and given as final recommendations to the ILC. He pointed to the experience of family members in Japan that was just presented by Dr. Ai Kurosaka. Despite the cultural and religious differences, there are a lot of similarities with the experiences lived by people in Brazil. These transnational similarities just need to be gathered. Second, with regard to the terminology, Morhan has 30 years of experience. It partnered with the academe to make its voice stronger. In Brazil, the first recommendation to change the term leprosy to Hansen's disease was made in 1976. It became a law only in 1995. Morhan has studied the impact of the change of terminology and has gathered scientific evidence. However, people did not listen to the request for the change in terminology and hence, the importance of addressing this issue.

Mr. Amar Timalsina of Nepal brought back the issue of how to identify the persons affected on the ground. He reiterated the need to have a word so that they can be identified. Dr. Cruz reminded everyone that the goal is for persons affected by the disease to go back to being called by their own names. There are patterns of human rights violation. Thus, it is all the more critical to have a strong identity in order to claim for rights, for example, women, people living with AIDS. Finally, she summed up that capacity building, fulfilling very basic needs, and access to work are all very important. She thanked everyone once again for all the work and wished that there was more time for a collective discussion.

Compensation Lawsuit Against the Government of Japan: Family Members of Hansen's Disease Ex-patients Speak Out

DR. AI KUROSAKA
Associate Professor, Tohoku Gakuin University

Dr. Ai Kurosaka

Dr. Ai Kurosaka greeted everyone and stated that she would read her prepared speech. As you know, on 28th June 2019, the Kumamoto District Court ordered the Japanese government to pay damages to family members of Hansen's disease (HD) ex-patients. Eleven days later, the government declared their intent not to appeal, and then Prime Minister Shinzo Abe officially apologized to the plaintiffs on July 24th for their pain and hardship resulting from the segregation policy and discrimination. She informed the audience that they can check these events in some websites since this became front-page news on many newspapers in Japan.

I am a sociologist and have interviewed HD ex-patients and their families for 15 years. After this suit, which I will call "the Family Members' Lawsuit", was filed, I submitted my written opinion based on my research to the Kumamoto District Court and gave testimony as a specialist of the Hansen's disease problem on the part of the plaintiffs. To make my written opinion and testimony, I was permitted to read the statements of all the plaintiffs. I attended the trial and participated in plaintiffs and lawyers' meetings when it was permitted. I would like to introduce you to the story so far, the details of the plaintiffs' appeal, and challenges facing Hansen's disease patients' family members today.

Family members filed suit 15 years after ex-patients' lawsuit victory

Before the Family Members' Lawsuit, there was a suit against the Japanese government seeking redress filed by HD ex-patients, claiming that the Leprosy Prevention Law and the segregation policy was unconstitutional. ("the Hansen's Disease State Redress Lawsuit"). In May 2001, the Kumamoto District Court decided in favor of the plaintiffs, and then Prime Minister Junichiro Koizumi apologized to Hansen's disease ex-patients. The judgement for plaintiffs became final and binding, and the plaintiffs delightedly said, "We have become human beings again!" After that, the Act on Payment of Compensation to Inmates of HD Sanatoriums was legislated by House members the next month, therefore all HD ex-patients including persons who didn't participate as plaintiffs became able to receive their redress. In 2009, the Act on Promotion of Resolution of Issues Related to Hansen's Disease was enforced.

DR. AI KUROSAKA is a sociologist and Associate Professor of Tohoku Gakuin University, Japan. For more than 15 years, she had interviewed persons affected by Hansen's disease and their families. She had compiled some stories from her study and published a book entitled, "Fighting Prejudice in Japan: The Families of Hansen's Disease Patients Speak Out," which was released in January 2019.

However, the Hansen's Disease State Redress Lawsuit and the Act on Payment of Compensation to Inmates of Hansen's Disease Sanatoriums dealt with the suffering which the ex-patients had experienced, not including the pain experienced by their family members. In addition, the Act on Promotion of Resolution of Issues Related to Hansen's Disease didn't address the family members' struggle. Family members were not considered victims of the Leprosy Prevention Law for a long time, even after the victory of the Hansen's Disease State Redress Lawsuit.

In 2003, the Hansen's disease patients' family member's association was organized for the first time in Japan, called Rengesou-no-Kai. It was the only association of family members in Japan at that time. In 2004, I became acquainted with Rengesou-no-Kai members. They had meetings once a year, and I was able to join their meetings every year as an observer. Rengesou-no-Kai had about 50 members, but only about 10 members had regularly taken part in their meetings. They came to the meetings from various places in Japan.
I realized that the family members were isolated in Japanese society. And I was certain that almost all family members in Japan had kept their silence.

> *"They told me the reason why they came to their meetings. They said, "Only at our meetings can we see other family members of Hansen's disease patients. Here we can talk about our own experience as family members, and our pain can be understood with sympathy by the other members. The most important thing is, there is no need to hide the fact that our parents (or siblings) were Hansen's disease patients."*

In February and March 2016, fifteen years after the Hansen's Disease State Redress Lawsuit victory, the Family Members' Lawsuit was filed as a class action. The plaintiffs had claimed that not only (ex-)patients but also their family members were victims of the Leprosy Prevention Law and the segregation policy. Although the original members of the action were Rengesou-no-Kai members, this family members' movement spread quickly and widely. 561 family members joined this suit. The fact that so many family members joined was a surprise to the Rengesou-no-Kai members and their lawyers (and me too, of course). On the other hand, almost all plaintiffs are anonymous in this trial (with only a few exceptions) and this shows that discrimination against them still exists. The plaintiffs and lawyers said there must be more Hansen's disease patients' family members who would not join this trial for fear of discrimination.

Dr. Kurosaka shared the stories of two of the plaintiffs in the lawsuit. Mr. Chikara Hayashi, 95 years old, was the leader of the plaintiffs. His father was sent to the national sanatorium when he was only 13 years old. The other was 63-year old Mr. Wang, a 2nd generation Korean resident in Japan, who was sent to a childcare institution when he was a baby after his two (2) elder sisters were sent to the sanatorium.

Plaintiffs' damage (1): Social status to be discriminated

Being a class action lawsuit, the plaintiffs side had to show to the court that there was damage in common among all the plaintiffs. 561 plaintiffs made their statements to the court one by one, telling their life stories and what she/he thought their own damage was. Each life story was unique, so it was not always obvious what her/his damage was, to the lawyers, and even the plaintiffs themselves. Through the cooperative work, the plaintiffs side derived two aspects of common damage among all plaintiffs.

The first aspect is that, the plaintiffs have been given a social status that is exposed to prejudice and discrimination caused by the Hansen's disease segregation policy. In 1931, the Leprosy Prevention Law required that every patient be interned in a sanatorium, and then the government and private sectors began a campaign to stir up fear of Hansen's disease as a dangerous disease. Public health centers disinfected houses of Hansen's disease patients and burned patients' belongings after their internment in the sanatoriums. Stirring up fear of Hansen's disease was harmful to not only patients but also their family members. They have suffered from prejudice and discrimination in various forms.

First, direct discrimination. For example, bullying at school, social ostracism, refusal of marriage or employment and so on. Plaintiffs of advanced age often had these painful experiences. Surprisingly, some plaintiffs in their 20s or 30s have experienced this direct discrimination too, especially refusal of marriage. Two sisters in their 30s both divorced because of discrimination. After their marriages, each sister told her husband that her father was a Hansen's disease ex-patient, and then each husband turned cold to her. The younger sister's divorce happened only 2 years before the filing of the lawsuit. Likewise, another plaintiff in his 30s divorced recently. After the filing of the Family Members' Lawsuit, he told his wife that his mother was a Hansen's disease ex-patient, and then his wife went back to her parents' house with their children. His mother said, "Kneeling down on the ground I begged my son's wife and her parents not to reject my son, but they looked down on me and refused."

Second, the struggle to keep secret. Most of the plaintiffs experienced this struggle to defend themselves or their families against prejudice and discrimination. For example, a woman in her 70s had hidden the fact that her parents had been in the Hansen's disease sanatorium from her children and her in-laws for a long time. She told them her parents had died. Because the sanatorium was some distance from her house, when she wanted to visit her parents, she had to give a false reason for her trip to her children and mother-in-law. She couldn't visit her parents often, and she couldn't do enough for her father in his last moments. Because of this regret, she finally decided to divorce to be able to take care of her aging mother. She said, "My life is full of lies. I have carried a feeling of sin on my back."

Third, not knowing the meaning of events occurring around them. Some plaintiffs didn't know the fact that their relatives were Hansen's disease ex-patients until recently. Their older relatives, especially the persons who were ex-patients, didn't tell them that fact to protect them from discrimination. As a result, they couldn't understand their own social position, the meanings of some events, and they were often confused. A certain plaintiff in his 50s, his father a Hansen's disease ex-patient, had not known that fact for more than fifty years. He said, "In my childhood, elementary school classmates often jeered at me with the word 'germ'. This happened to my younger sister too. I didn't know why they called us that, so I didn't realize this situation was discrimination. My father would never touch me, and I have never held hands or taken a bath with my father like ordinary parents and children. I felt sadness and I became a violent boy when I was in junior high. The classmates stopped calling me 'germ', but no one became friends with me. It was only a few years ago that I knew the fact that my father was a Hansen's disease ex-patient. My relative told me, when she heard about the Family Members' Lawsuit, 'you are qualified to be a plaintiff.' I spoke with my father, and he told me his true story, crying for the first time. He had worried about giving Hansen's disease to me, it was the reason why he wouldn't touch me. Now I know the reason why I had to spend such a lonely childhood, and I feel so sorry for my father. I hope my father understands why I always did troubling things to him. My father and I have started to rebuild a parent-child relationship."

Plaintiffs' damage (2): Deprivation of the family relationship

The second aspect of 'common damage' is that the plaintiffs have been deprived the family relationships from the influence of the Leprosy Prevention Law and segregation policy. This damage arose in several ways.

Physical separation from their relatives who were interned. Families were torn apart under this situation, and many plaintiffs were deprived of their parents, siblings, children, or partners. A certain plaintiff in her 70s was separated from her parents when she was 8 years old. Her parents were in a Hansen's disease sanatorium, and she was left with her aunt (her mothers' younger sister). Her aunt had divorced because of discrimination and had her own two children. Her aunt was very poor and made her do housework, cooking with a wood-burning stove, washing clothes in the river, weaving traditional cloth and so on, and gave her very little emotional support. She said, "I was all alone. I was a Hansen's disease orphan."

Mental evasion by internalization of dangerousness of

Hansen's disease. Ex-patients often avoided touching infants directly because of an ingrained caution, although they already knew Hansen's disease was not dangerous. Family members also sometimes avoided their relatives who were patients, because of this ingrained fear of HD. A man in his 80s whose father was an inmate of a Hansen's disease sanatorium, said, "When my father visited my house from the sanatorium, I separated my father's dishes from everyone else's. I myself discriminated against my father. I have strongly regretted this for a long time." He was talking while crying. The man spent his childhood in the nursing facilities for Hansen's disease sanatorium inmates' children. The fear of Hansen's disease was put into his mind there, and he couldn't wipe that away even after becoming an adult.

Finally, hating or blaming their own relatives as the cause of the discrimination. They had been discriminated as 'Hansen's disease family members', so they sometimes hated and blamed their relatives who were patients, as the cause of their suffering. Discrimination destroys human relationships, and not only patients but also their family members struggled in this situation. A woman in her 70s whose father was a Hansen's disease patient, told her sad story. "When I was 3 years old, my father was interned in a sanatorium, and then my mother married another man. I was brought up by my relatives. They hated me, and I grew up without knowing family love. After I met my father again, I blamed him for my suffering, and I hated him as I had been hated. Now I regret how I behaved toward him, and I have deep pain about hating my own father."

'A bitter victory judgement' and apology from the Japanese government

On June 28, 2019, the Kumamoto District Court decided in the plaintiffs' favor. This decision had both a good point and bad points (Yasuyuki Tokuda, the representative of the plaintiffs' lawyers, expressed this complicated decision as "a bitter victory judgement"). The good point is that the court found that the government was liable for the family members' damage. The court said, although the Leprosy Prevention Law had to be abolished in 1960s at least, the government and House members had neglected that matter. And the government didn't fulfill their responsibility for elimination of prejudice and discrimination. The court made its judgment that not only the Health, Labor and Welfare Ministry but also the Justice Ministry and the Education, Culture, Sports, Science and Technology Ministry were responsible for failing to work to protect the rights of Hansen's disease patients' families.

One of the bad points is that the compensation for damage was insufficient. The court divided the plaintiffs into some groups for compensation payment, and the amount for the highest group was 1.3 million yen, although the plaintiffs side claimed 5 million yen per head. Only 0.3 million yen was the amount for two-third of the plaintiffs. 20 peoples of the plaintiffs were rejected their claim. Another bad point is that the court reduced the compensation payment for Okinawan plaintiffs. The court said the Japanese government was not to blame about Okinawan plaintiffs' damage until 1972, because It was American occupation period until then. After the decision, the plaintiffs side released their statement which criticized this discriminatory judgment.

In July, Prime Minister Shinzo Abe declared the government's intent not to appeal, and officially apologized to the plaintiffs. He promised to start a discussion to take steps about recovering of all the family members' damage, including persons who didn't participate as plaintiffs. Diet deliberations about this matter will start in this autumn. We will have to keep an eye on the Diet deliberations.

Although Prime Minister apologized, it cannot be said that the difficult situation in which the family members live has changed.

> “*We Japanese citizens must change the social situation in which the family members have to hide the fact that their relatives were Hansen's disease patients and have to keep silence, by eliminating of discrimination. If that comes true, the family members will be able to recover the relationships between their relatives who were Hansen's disease patients without anxiety about discrimination. The challenge has only just begun.*”

Dr. Kurosaka ended her sharing by asking the delegates to read the stories in her book "Fighting Prejudice in Japan: The Families of Hansen's Disease Patients Speak Out" and thanked everyone for their kind attention.

Developing Sustainable Livelihoods and Organizations through Social Entrepreneurship

DR. MARIE LISA M. DACANAY
President, Institute for Social Entrepreneurship in Asia (ISEA)

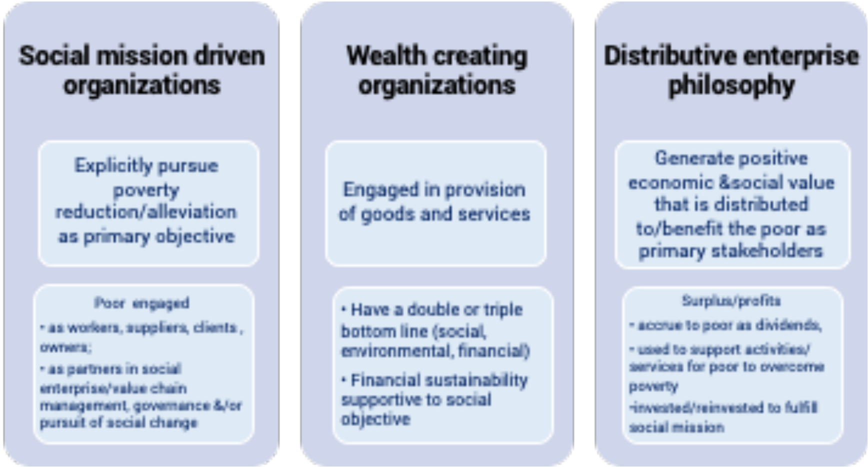
Dr. Marie Lisa M. Dacanay

Social enterprises are a relatively new phenomenon. Based on a research of 50 countries, two definitions of social enterprises emerged. First, social enterprises are "responses towards new ways of sharing responsibility for the common good in today's economies and societies". The reason they are new ways is because the old ways, especially of doing business, or development work, are not enough to meet the challenges of people particularly those who are marginalized and poor. Second, social enterprises are defined as "responses on the basis of economic/business models driven by a social mission". In this definition, what is new is that social enterprises are like businesses since they make money. However, unlike businesses, they are like NGOs because they are driven by their social mission.

In the research that ISEA had done in India, Bangladesh, Philippines, and Indonesia, the study identified three key elements of social enterprises that serve the poor or marginalized sectors of society. First, social enterprises that serve the poor or marginalized sectors of society are social-mission driven enterprises. The poor are engaged in the enterprise as workers, suppliers, clients, or owners. However, the poor are also engaged as partners in the social enterprises or in value chain management, governance and/or pursuit of social change. Second, social enterprises are wealth-creating organizations. They are engaged in provision of products and services to various people and markets. Third, unlike ordinary businesses, social enterprises have a distributive enterprise philosophy. This means social enterprises create wealth and distribute that wealth to the poor and marginalized who are their primary stakeholders. In this sense, they are like hybrid organizations.

Social enterprises and private businesses are different in three ways (Dacanay, 2004; 2013). First, the beneficiaries of private businesses are usually the stockholders who invest in capital. These stockholders invest their capital in order to enrich themselves. The social enterprises, on the other hand, have the poor or marginalized sectors beneficiaries. Second, the primary objective of a business is profit. Even those whose businesses have corporate social responsibility, if the profit is at stake, they will chose profit. SEs, however, have double or triple bottom-lines. They have a financial bottom-line as well as a social one. SEs want to be sustainable and they need to strive to be sustainable while pursuing their social mission. Third, ordinary businesses accumulate wealth for stockholders. SEs create and distribute the wealth that they create.

DR. MARIE LISA M. DACANAY is the founder and President of the Institute for Social Entrepreneurship in Asia (ISEA). She is pioneer in entrepreneurship in education and research in the Asian region. She has over 20 years of experience in development management and consultancy in social enterprises in the Philippines and other countries in Asia.



Social mission driven organizations	Wealth creating organizations	Distributive enterprise philosophy
Explicitly pursue poverty reduction/alleviation as primary objective	Engaged in provision of goods and services	Generate positive economic &social value that is distributed to/benefit the poor as primary stakeholders
Poor engaged • as workers, suppliers, clients , owners; • as partners in social enterprise/value chain management, governance &/or pursuit of social change	• Have a double or triple bottom line (social, environmental, financial) • Financial sustainability supportive to social objective	Surplus/profits • accrue to poor as dividends, • used to support activities/ services for poor to overcome poverty •invested/reinvested to fulfill social mission

Examples of Social Enterprise Models

The following are examples different social enterprise models.

1. Children are Us Social Welfare Foundation (Taiwan)

Its mission is to inspire and promote the potential talent of people with intelligence disability (PID) to assist their return to social mainstream to enjoy the dignity and happiness of life. It has a social welfare department serving at least 300 PIDs. Its business department manage a world-class bakery and restaurant where the PIDs, their primary stakeholders, are employed. Over 50% of the foundation's revenue come from the sales of this world-class bakery and restaurant. The social entrepreneurs behind the Children are Us Foundation are mothers of the PIDs. They are people with business skills who set up the foundation. They learned the art of using business in the service of PIDs.

2. Tahanang Walang Hagdan or House with no Steps (Philippines)

Its mission is rehabilitating the physically disabled people to enable them to have gainful and productive lives. It has sheltered workshops that produces products and services that are sold to various markets. It has metalcraft, woodcraft, and needlecraft workshops. It also has a workshop for packaging medicines for pharmaceutical companies. Tahanang Walang Hagdan works with markets that need certain products. They also produce many educational toys that are sold in schools. In 2009, these sheltered workshops had 309 persons with disability (PWDs) and 90 office-based workers. It has a business center that assists in the development and marketing of products made by PWDs.

Tahanang Walang Hagdan trained the PWD micro-entrepreneurs who have the savviness and want to be entrepreneurs. Its board members consist mainly of people from the religious sectors. Some members come from the private and business fields. The management team of Tahanang Walang Hagdan used to be business people who were not PWDs. This changed when the organization made a conscious effort to get PWDs to take over supervisory tasks then afterwards, the managerial functions.

3. National Federation of Cooperatives of Persons with Disability (NFCPWD)

As a federation, the NFCPWD is composed of cooperatives at the local level whose members are PWDs. The NFCPWD set up an enterprise to build and sell school chairs to schools and to the country's Department of Education. PWDs make quality school chairs. Despite being a cooperative, the NFCPWD started with one person directing and making the decisions for the enterprise. Over time, the training and development of the members of these cooperatives helped them to become pro-active. When ISEA studied these member cooperatives, different cooperatives were at different stages of development. In developing countries like the Philippines, many do not even finish elementary education unlike in Europe where everyone completes high school education and is prepared for life. From NFCPWD's experience, the important lesson is to have a conscious effort to train and develop members so they can understand how to make decisions, how to become proactive members, and eventually, how to become leaders.

The NFCPWD also decided that they needed to set up a Foundation for These-abled People (FTI). The most empowered PWDs worked with supporters (e.g. CBMI, CCA, Rabo Bank) who were non-PWDs. Together they set up FTI that helps to build social enterprises of PWDs. The inclusion that needs to happen is a process where persons not affected by Hansen's disease could help those affected to help build inclusive foundations as in the case of the FTI that works to build SEs of PWDs.

4. Gandang Kalikasan Inc.

Gandang Kalikasan Inc (GKI) manufacture and sell personal care products under the label Human Nature to various markets. It has physical stores and its products are also available in supermarkets and malls. GKI consciously recruit workers, who do not have the skills to be employed, from the marginally poor communities. Afterwards, GKI trains and develops them to become Human Nature workers. Moreover, GKI pays these workers a "living wage" and benefits. At a time when the minimum wage in the Philippines was about Php500, GKI was paying its workers around Php850. It does not have a firing policy. Once someone becomes a Human Nature worker, one is not fired but one is retrained or relocated within the company.

GKI has a program for workers' empowerment composed of four (4) dimensions: (i) Freedom from indebtedness and sound personal financial management; (ii) Quality of Life; (iii) Workplace Transformation; (iv) Spirituality and Involvement in Community Development. GKI is a family corporation. The owners have committed their lives to work and care for the poor true to their Pro-Poor, Pro-Environment, and Pro-Philippines advocacies.

5. Dragon Vietnam (DVIC)

Dragon exports fresh and processed ginger. Its products meet the standards of GAP, which means good agricultural practices. DVIC has enabled 2,000 indigenous women and men among the H'mong people in Vietnam to become members of Interest Groups who sustainably cultivate ginger. These indigenous peoples only used to cultivate corn but DVIC introduced ginger as a means of diversifying their sources of livelihood. Since ginger is a high-value crop, it can be sold in the international markets. As a result, the indigenous people's income increased by 5-10 times more than what they were earning from cultivating rice and corn only.

Dragon helped these farmers by providing the inputs, trainings and continuing technical support. Then, it commits to buy all their produce with DVIC taking the risks. When DVIC buys from the farmers, they use a flexible market rates that is high when market prices are high. When market prices are low, DVIC still buys from the ginger farmers but at a minimum purchase price or agreed floor price to protect the ginger farmers when prices are down. DVIC also promotes sustainable agriculture and forestry, biological composting and non-usage of herbicides.

6. Alter Trade Foundation Inc. Negros & Fair Trade Association (NOFTA) and NOFTA Fair Trade House

The model of Alter Trade Foundation Inc. (ATFI) or Alter Trade is that of a foundation, cooperative, and corporation working together. This is a social entrepreneurship intervention where different actors and social enterprises are working together to improve the lives of the poor and marginalized workers turned agrarian reform beneficiaries. Alter Trade transformed 700+ women and men agricultural workers/beneficiaries of land reform to become entrepreneurial farmer-leaders and members of cooperatives/associations serving as supplier communities of organic muscovado sugar value chain. It helped the agrarian reform beneficiaries to diversify their crops and incomes. It contributed to the development of the community's visioning, planning, and implementation.

> *"These examples of social enterprises show the different models that could be combined when people's organizations on Hansen's disease start thinking about sustainable livelihoods and how to become more sustainable in serving persons affected with Hansen's disease."*

Common External & Internal Challenges

Among the more common external challenges that social enterprises face includes:

a. Extreme weather disturbances
b. Government policies negatively affecting social enterprises
c. Industry/market practices negatively affecting social enterprises
d. Inadequacy of programs supporting social enterprise development
e. Corruption in government regulatory bodies

These problems show that if social enterprises are to succeed, they need to create a policy environment that is favourable for their growth. In many countries, they are promoting a social enterprise law. Korea is one of the first countries to pass such a law followed by Thailand. The Philippines has been lobbying for a similar one since 2012. Social enterprises need to work together to change market practices and to change government policies.

Some of the important internal challenges that social enterprises have to overcome are:

a. Access to appropriate technologies
b. Access to adequate financing
c. Capacity development among leaders, managers and people
d. Effective and efficient management and operations to meet volume and quality requirements of markets
e. Measurement of social impact/outcomes

These challenges can best be solved by capacity building. Social enterprise management is more complicated than a normal business since it requires the balancing of the financial and the social objectives. It is high time to develop social entrepreneurs among people affected by Hansen's disease. Since developing people take time, people's organizations could collaborate with social entrepreneurs in the meantime.

Models of Social Enterprises

Based on the examples discussed and the research in 50 countries, three models were shown to be the most dominant in Asia.

a. Entrepreneurial Non-Profit Model: has a social and financial side
   - ◊ Children Are Us Foundation (Taiwan)
   - ◊ Tahanang Walang Hagdanan (Philippines)

b. Social Cooperative Model: looks into the benefits of the communities
   - ◊ National Federation of Cooperatives of Persons with Disability (Philippines)

c. Social Business Model: corporations that act differently and has a social mission
   - ◊ Gandang Kalikasan/Human Nature (Philippines)
   - ◊ Dragon/DVIC (Vietnam)

d. Social Entrepreneurship Intervention combining the 3 models
   - ◊ Alter Trade Foundation, NOFTA and NOFTA Fair Trade Haus (Philippines)

Services Provided by Social Enterprises

Social enterprises are hybrid organizations that provide hybrid services. These services are classified into two:

1. Transactional services - Assist the poor to become effective and efficient workers, suppliers, clients (roles performed by poor involving exchange of goods or services for money). These are the services that the market need.
2. Transformational services - Enable the poor to become conscious agents of change to improve their quality of life and that of their community, sector, or society as a whole. An example is Alter Trade Inc. Every supplier community that it assists go through community mapping, visioning, and implementation of their community plans. These are transformational services.

Concluding Remarks

Social enterprise development may be useful for people's organizations of persons affected by Hansen's disease as they confront issues of sustainability. They need new ways of facing these sustainability issues. Social entrepreneurship and social enterprise development are new ways that can be incorporated and has shown to be effective in working with marginalized people.

Different segments, needs, and contexts of persons affected by Hansen's disease may entail the development of one or a combination of social enterprise models. Whatever may be the model chosen, persons affected by Hansen's disease have to be capacitated as pro-active partners/empowered stakeholders by providing both transactional and transformational services.

> “*Social enterprise development requires a new set of knowledge, skills, attitudes and aspirations for people's organizations of persons affected by Hansen's disease and a systematic capability building program if these are to be incorporated as a program and a strategy.*”

There is potential for government and intergovernmental bodies to play a big role especially given the 2030 Agenda for Sustainable Development. Governments would need to be lobbied if they are to provide an enabling environment for social enterprises serving poor and marginalized sectors including persons with Hansen's disease. People's organizations of Hansen's disease should also reach out to the business sector, social entrepreneurship practitioners, social enterprise resource institutions, and retired businesspeople wanting to help the poor and marginalized and build a network while building their capabilities for social entrepreneurship.

Dr. Dacanay ended her presentation with these words from the Australian Commission for the Future: “The future is not some place we are going to, but one we are creating; the paths to it are not found but made; and the making of those pathways changes both the maker and the destination. “

In photo: Dr. Lisa Dacanay deep in conversation with a Global Forum delegate

WORKSHOP I

Guide Questions for Workshop on Sustainable Livelihood Development:

1. What is the state of livelihood and employment for persons with leprosy in your respective communities? What issues and problems do they face in terms of livelihood and employment?
2. How are your people's organizations and other institutions/actors responding to these issues and problems? What initiatives have been done, are being done or could be done to respond to these issues and problems?
3. What do you think are the potentials and opportunities for your people's organization to directly undertake or to partner with other organizations/actors to pursue social entrepreneurship for sustainable livelihood development?
4. What should be done by key players to support these initiatives?

SUMMARY OF WORKSHOP RESULTS

Livelihood and Employment Issues & Problems

Based on the outputs of the two (2) groups assigned, the main issues and problems covered personal ones such as poverty, stigma and discrimination, mindset of dependency, physical deformities/disabilities while the organizational issues were lack of education, lack of technical skills and knowledge (e.g. marketing) and lack of capital.

Responses to the Issues & Challenges

Among the initiatives that people's organizations and other institutions/actors have done to respond to these challenges were providing education, conducting trainings/awareness on elimination of forms of stigma/ discrimination, providing microcredit/ loans for small scale businesses, and access to market, building capacities, empowering members, networking and forming partnerships with other organizations, and offering physical rehabilitation services.

Potentials & Opportunities for People's Organizations

The potentials and opportunities for people's organization to directly undertake or to partner with other organizations/actors to pursue social entrepreneurship for sustainable livelihood development that were identified could be grouped into internal and external. The internal strengths include unity of self-help groups, collective knowledge and strong will, the 4Cs (coordination, collaboration, capacity building and cooperation). The external opportunity is the presence of technology (social media), access to government services (e.g. Job fairs, etc.), partnership with International NGOs, and global network.

Key players' Role/Actions

To support these initiatives, key players could give training and mentoring, provide funds and technical support, capacity building, establish favorable policies and guidelines, and help in accessing marketing opportunities. One of the groups cited developing a global charity market for people's organizations products/services.

In photo: Participants from the various regions discussing during the Sustainability workshop

WORKSHOP 2

Guide Questions for Workshop on Organizational and Financial Sustainability

1. What are the issues and challenges that your people's organizations are facing in terms of organizational and financial sustainability?
2. What are you and other actors doing to address these issues?
3. What do you think are the opportunities and potentials for developing your respective organizational and financial sustainability plans? Do you see any role for social entrepreneurship/social enterprise development in these efforts to achieve organizational and financial sustainability?
4. What should be done by key players to support your efforts to achieve financial and organizational sustainability?

SUMMARY OF WORKSHOP RESULTS

Organizational and Financial Sustainability Issues & Challenges

People's organizations are faced with a variety of operational and strategic issues with regard to their organizations. These include identifying the most appropriate enterprise/livelihood, coming up with quality products, market linkages, and lack of capacity to meet the requirements of national and international markets (e.g. management, legal documents, etc.). Their organizations are donor dependent if not unstable financially, and lacked capacity in resource mobilization. Many lacked committed and permanent staff, and lacked management, financial and business know-how. Good governance and leadership/management is a big challenge. The groups also mentioned the lack of volunteers for their organizational activities.

People's organizations and persons affected by Hansen's disease face physical challenges, lacked education, vocational skills as well as communication skills. They are afraid of the stigma and discrimination with regard to their products, and of the high demand and expectations of members. The groups also cited competition for power and the lack of government transparency/unfavorable policies among their other challenges.

Addressing the Issues & Challenges

People's organizations and other actors are giving training on human rights, management skills, specific job skills, and proper documentation and monitoring to address the issues and challenges in relation to organizational and financial sustainability. They also provide counseling, leprosy self-help care, and conduct literacy programs. Group 5 presented the initiatives in each of their countries.

- ◊ Columbia: Its government procure from companies of people affected by Hansen's disease and provide health services.
- ◊ Nepal: Its government allocated a small budget for people affected by Hansen's disease.
- ◊ India: Its government offers (i) regular grants; (ii) provides capital at low interest rates; (iii) support marketing system (with land, electricity at concessional rates); (iv) tax concession for first 5 years.
- ◊ Bangladesh: Its government gives(i) grants, loan without interest from government; (ii) land at low price; (iii) skills training.

Potentials & Opportunities for Sustainability Plans

Among the opportunities and potentials for developing their organizational and financial sustainability included good leadership, organizing the members and developing their negotiation skills, and giving them vocational training. Organizations could generate more income if they could identify sustainable and viable projects. For instance, social enterprises (e.g. animal farming) was one of the initiatives identified to achieve organizational and financial sustainability.

People's organizations could also look into developing a taskforce within their group that will focus on networking in order to mobilize resources/funding. They also need to ensure that they have a legal entity that their governments can support.

Key players' Role/Actions

To support the people's organizations' efforts to achieve financial and organizational sustainability, the key players could give technical support, grants and loans, capacity building through ongoing education or regular training of staff at all levels, and assistance in developing and submitting proposals. Moreover, they could identify potential local partners and help in establishing partnerships as well as share their

In photo: A mixed group of participants during the Sustainability workshop on Day 2 of the Global Forum

experiences and best practices. They could also assist in advocating with government for favorable policies.

IDEA Korea which engages in poultry farming was able to lobby the Korean government for the army and police force to buy the products of this farm. In Kenya, the government has a policy that 30% of government procurement should be sourced from youth, women and organizations of PWDs. These examples illustrate the various partnerships that could be made by people's organizations on Hansen's disease.

COMMENTS/FEEDBACK FROM DR. LISA DACANAY

The different groups reported repeatedly on stigma and dependency mindset among the challenges faced by people's organizations on Hansen's disease. The mindset of social entrepreneurship could be an alternative mentality. Social entrepreneurship is a mindset change that will require a plan quite different from what the delegates were used to. It is a mindset shift that could be appreciated at this point. It may be a way to if people are ready to do things differently from what they are used to.

Most of the groups talked about networking and partnerships but mainly with the government and NGOs. Not surprisingly, the social enterprise sector (i.e. social enterprises and social enterprise resource institutions) was not in many participants' minds. To create a social entrepreneurship mindset and work towards innovations it is important to work with social enterprise practitioners and link with social enterprise resource institutions. Capacity building was also defined as a way but no one talked about capacity building for social enterprises.

On sustainable livelihood development, a group proposed developing a global charity market. Several questions that comes to mind with this proposal: What is a charity market? Would this market not foster another dependency relationship since it will nurture a market that has the perspective of charity in mind? In social entrepreneurship, equitable and fair markets are what is fostered. In social enterprises, there are what are called fair trade organizations, which promote new ways of trading.

In relation to organizational and financial sustainability, some of the challenges that are operational or strategic in nature and could be resolved by the organizations with their existing partners. Many of the proposals were focused on improving what the organizations are already doing. New partnerships or new initiatives could help enhance the organizations' sustainability plans beyond the strategic and operational issues that they can resolve with government and NGO partners. With the introduction of the people's organizations on Hansen's disease to the social enterprise sector, these could explore such partnerships with social enterprises. Dr. Dacanay is looking forward to exploring possibilities of new collaborations. She that new partnerships in sustainable livelihood development as well as in sustaining the organizations of persons affected by Hansen's disease can be incorporated in future initiatives and discussions.

QUESTIONS & SHARING

1. Dr. Cunanan: Most of the organizations are familiar with the issue of sustainability. Is there an appropriate social enterprise model that you could recommended that would fit the group considering the background of the people's organizations? Given the disparity or variability in terms of the geography and capacities of the organizations, if I am an organization, where or how do I start?

Dr. Dacanay: Based on my limited conversations with the participants, there are existing cooperatives that have been set up by persons affected with Hansen's disease in India and perhaps, in other places. She recommended documenting these cooperatives set up set up by persons affected with Hansen's disease in various countries and other initiatives. I am an advocate of action research and I believe a good starting point is to begin where the organizations are. In this way, the recommendations that could help transform these cooperatives into social cooperatives would be realistic, helpful and relevant. She reiterated that the way forward is through action research. In terms of self-help groups, these are at the pre-cooperative formation stage. To respond to the need for livelihood development, these could be documented, synthesized and make recommendations on how to invigorate so that these become social cooperative models that are relevant to persons affected by Hansen's disease.

With the entrepreneurial/non-profit model and the social business model, I did not hear of any initiative by persons affected by Hansen's disease that are linked to entrepreneurial/non-profits model that have achieved a scale. Although I heard that there are international NGOs working with persons affected by Hansen's disease, these have come close to the best practices of the entrepreneurial/non-profit enterprises like Children Are Us Foundation in Taiwan or Tahanang Walang Hagdan in the Philippines. Be exposed to real social businesses or entrepreneurial/non-profits so that you can start thinking how those business models would be relevant to you. We could start with developing a networking program. This network will start with identifying social enterprises and social enterprise resource institutions in the various countries where the level of social entrepreneurship would be feasible as a new way of doing things. It could then be followed with developing partnerships at the local level and creating a specially-designed course that can be piloted at the regional or global level. Afterwards, the course could be delivered at the national or local level. I cannot prescribe any model that would be appropriate or relevant since these need to come from the persons affected by Hansen's disease. Brainstorming could be done after exposure to these social enterprise models.

On the question of how to start, changing mindsets is the first thing that needs to be done to the point where social entrepreneurship is the mindset of leaders and members of people's organizations on Hansen's disease. Social enterprises or social entrepreneurship will not resolve everything. Social enterprises cannot do what NGOs can do best such as community organizing or advocacy. Social enterprises can help organizations of people affected by Hansen's disease if the objective is enhancements in providing sustainable livelihood as well as developing financial sustainability strategies for the organizations. Working together with existing partners would be more appropriate to resolve strategic and operational issues that people's organizations are facing. Social cooperatives is an important form of social enterprise that empower people form the marginalized sector. Action research would be relevant to surface initiatives among organizations of persons affected by Hansen's disease would be an important step moving forward.

2. Ms. Franciline Mesquita (Brazil): She asked how anyone could produce and sell products if faced with stigma in relation to the products they are selling. Should there be information campaigns about the products being sold?

Dr. Dacanay: The way would be to develop ethical markets or fair markets as a whole. Fair trade organizations have realized that they cannot promote "pity buys". Consumers do not buy a product because one pities the producer. Fair trade organizations have become better in developing products and services than their commercial counterparts. People affected by Hansen's disease should be effectively trained to make very good products. What needs to be done would be to create ethical markets. This means people want to buy the products or services because they are good and come from ethical value chains.

From ISEA's studies of success and failure stories of social enterprises, a single enterprise-framed does not go very far. Forty percent (40%) of microfinance clients fall out every year. Microfinance institutions have realized that they need to provide value chain services so that their social enterprise initiatives are more sustainable. In order to create successful social enterprises, need to develop social enterprises situated in specific economic situation and economic sub-sectors. Markets are changing all the time. Economic sub-sectors and value chains need to be studied. It is not just a question of having a product and selling it to a specific market. Research is needed to find out in what value chains and economic sub-sectors persons affected by Hansen's disease are situated and could be major players. There is a need to map out the resources available, the capacities of people, and where the organizations are in terms of livelihood. All these would help in understanding where there are opportunities and potentials for growth.

Even with the proposed social entrepreneurship bill in the Philippines, the PRESENT Coalition is pushing the government to make economic sub-sectors as units of planning social entrepreneurship interventions. In different countries, persons affected by Hansen's disease can be major players. Fair Trade organizations are a product of years of development. The participants could learn from what did so they are no longer dependent on pity buys. Fair Trade organizations are able to get premium prices for the products created by marginalized people. The basis for the capacity building course on social entrepreneurship would be to learn from the experiences and insights from other marginalized sectors.

3. Mr. Paulus Manek (Indonesia): Regarding the sustainability of organizations: On a scale of 1 to 10, where 1 is not good and 10 is very good. If an organization is still at the basic level, what is the good example that I could bring to my country?

Dr. Dacanay: The proposal is begin with an action research, which is not academic research. It can help in developing responsive strategies and programs. It includes exposure to successful social enterprise models in different countries where they exist and a specialized course for persons with Hansen's disease to develop their social enterprise mindset as well as social enterprise knowledge, skills, attitudes and aspirations.

4. Mr. Paulus Manek of PerMaTa Indonesia shared that the organization did a participatory needs assessment three (3) years ago. The study came up with very good results. The organization lacks the capacity for knowledge management. It also does not have the capability for developing proposals with a good structure, the needed quantitative and qualitative metrics, and methodologies. He agreed that action-research could be a good starting point for more sustainable people's organizations.

Dr. Dacanay: Operational and strategic issues could be resolved by the organizations themselves and/or with existing partners. The enhancements that ISEA could bring in is to develop new initiatives and new partnerships.

Dr. Nanri: Firstly, Dr. Dacanay has already presented the various models of social enterprises. However, the situation of organizations differ from country to country. It is important for PerMaTa to know which model is applicable to the organization. PerMaTa is the best one to know which model is the best. There may be some other organizations or people could assist PerMaTa on the operational issues and capacity building. He suggested that PerMaTa study what social enterprise model is applicable to it and to start by doing research on the organizations around. What Dr. Dacanay had suggested is action-oriented research or fact-finding to put it more simply.

5. Mr. Joshua Oraga (Kenya): The people's organizations in the African region view the social enterprise approach as one of the things that they would like to take away from this Forum. However, he pointed out that the level of development of people's organizations in the African region is a little lower than those in other regions. Going forward, he would like to request that another forum be put up to analyse the African situation, the opportunities there and to see how to develop the capacities in social entrepreneurship as people's organizations.

In photos: (left) Sustainability Session Group Presentation, (right) Dr. Marie Lisa Dacanay and Dr. Takahiro Nanri

KEYNOTE SPEECH


Mr. Yohei Sasakawa

MR.YOHEI SASAKAWA
Chairman, The Nippon Foundation
WHO Goodwill Ambassador for Leprosy Elimination

"I was informed that there are many different languages being spoken here today, and that people are using interpreters. So I intend to speak very slowly and make my sentences very short.

First, I would like to welcome all of you who have come for this meeting. I have heard that there are 60 leaders from 23 different countries gathered here.

> ***Having this kind of forum with so many persons affected by Hansen's disease all together, is truly significant.***

It bodes well for the future. Thank you once again for coming to this meeting, and from very far away in some cases. All of the activities that you are doing in your countries are meaningful and are making a difference around the world.

Persons affected by Hansen's disease have suffered for a very long period. Your views and your participation are going to be a very important guide as we seek to find solutions to the issues that you are facing.

If you consider a single strand of yarn: it is weak, like one person's voice is still small. But when that single strand of yarn is braided together into lengths of 10, or 100, or 1,000 strands, then it becomes part of a strong rope—much stronger that a single strand.

I think you all already know that back in 2010, a resolution on elimination of discrimination against persons affected by leprosy and their family members, together with accompanying Principles and Guidelines, was adopted unanimously by 192 countries at the United Nations General Assembly.

In order to make that happen, we lobbied the United Nations for more than seven years years in order to convince first the UN Human Rights Commission and later its successor, the UN Human Rights Council, in Geneva, to pass a resolution. To achieve that grand objective, a central role was taken on by Mr. Tanami from The Nippon Foundation in order to help develop the contents of the Principles and Guidelines that accompanied the resolution. I want to take this opportunity to thank Mr. Tanami for his hard work.

MR. YOHEI SASAKAWA is the Chairman of The Nippon Foundation and the World Health Organization's (WHO) Goodwill Ambassador for Leprosy Elimination to contribute to its efforts in relation to leprosy related problems and solutions. In his capacity as WHO Goodwill Ambassador since May 2001, he has visited more than 90 countries and met over 150 national leaders such as presidents, prime ministers and other national leaders. He shares his thoughts with them and gains their understanding and commitment toward Leprosy.

On top of that, we have a UN Special Rapporteur, Ms. Alice Cruz, who has been working very hard to resolve the issue of discrimination against persons affected by Hansen's disease that still exists worldwide. Despite her very busy schedule she has come all the way to participate in this meeting.

While she is here, I would like each of you to talk with her about the situation in your country as well as the various measures your government has been taking to end discrimination, so that she will be able to understand the situation in depth. This will enable her to write up the details in her report to the UN Human Rights Council. She is very passionate about her work.

Is there anyone who wants to talk to her about their situation? (The participants were asked to raise their hands). There are many hands. Alice, you will be very busy!

The resolution that was adopted at the UN General Assembly in December 2010 was a very big step forward for us. However, this does not mean that it is legally binding, even though it was given unanimous backing by member countries.

I would like you to thoroughly familiarize yourselves with the contents of both the resolution and the accompanying Principles and Guidelines in your own language. This is so that whenever you have a gathering with your leaders or whenever you have the chance to talk to the media, you will be able underline the facts and help them to understand what the Principles and Guidelines are all about and why they are so important.

When we look back over history, there is no other disease that has had such devastating consequences on the lives of those it affects than Hansen's disease. Throughout history, persons affected by Hansen's disease have had their human rights denied them. They have found themselves placed in the most terrible circumstances.

But now is the time when your voices are being heard loud and clear, calling us to action. This is the reason why this forum is being held. This is the reason why organizations of persons affected by Hansen's disease have been formed. I hope that more members will join your organizations so that your voices become louder still.

In the countries that you represent here as leaders of your organizations, I am sure each of you has serious issues that you are faced with in society. I urge you to share these issues with people here so that you will be able to find solutions and join forces in the future, and so that society will take note of your actions and your voices. You are the ones who are helping to resolve the issues of stigma and discrimination facing persons affected by Hansen's disease.

Jennifer is going to report on what was discussed at this forum at the International Leprosy Congress that begins the day after tomorrow, and we are looking forward to what she has to say. Let us all cooperate with her and support her so that the report will be very influential.

Let me say finally that I am proud that I am able to join this battle with all of you.

> “*I turned 80 this year, but I am still participating in the battle with you, and this is a huge source of pride for me. Let us fight together!*”

In photos: (left) Dr. Alice Cruz with Mr. Yohei Sasakawa, (right) Some participants performing at the dinner hosted by Mr. Sasakawa.

Addressing the Remaining Challenges: Towards A Leprosy-Free World

DR. ARTURO C. CUNANAN JR.
Medical Center Chief I, Culion Sanitarium and General Hospital


Dr. Arturo C. Cunanan, Jr.

"Giving this lecture is a measure of empowerment," Dr. Cunanan stated. A lecture on public health was usually among public health workers, among specialists, clinicians or researchers. "It is a great opportunity to speak to the people affected by the disease". I remember saying "nothing about us without us."

Time to Think Again

People and policymakers believe leprosy has been eradicated. Many are confused with the term elimination and eradication. New cases continue to be detected up to the present. People's organizations face the huge task of advocating for the sustainability of leprosy services among policymakers. There is a great need to advocate that though leprosy is communicable, it is curable when detected early and adequate treatment with multi-drug therapy (MDT) is provided.

Leprosy is stigmatised. Stigma is not only associated with the skin patches, deformities and disabilities. In fact, social stigma facilitates the transmission among vulnerable groups including migrant populations, and displaced groups. Leprosy-related disability limits activity and leads to restrictions in social participation. The disease and its stigma attacks more than just the body. It damages the whole human person with leprosy at the physical, emotional, and psychological levels. The stigma, based on ignorance, is dehumanizing because the rejection, humiliation, and banishment leads a person with leprosy to questions one's full humanity.

Stigmatization and discrimination in public health is a major barrier to (i) timely detection of the disease; (b) treatment completion and follow up; (c) household contact screening and prevention of disabilities. In the Pacific, the culture and stigma is very different. There was a person affected by the disease who did not want to be visited in her house because the husband did not know she was sick of leprosy. She was afraid that if the husband learns of her sickness, he would leave her. A patient in Kiribati was asked by his father-in-law, upon learning he has leprosy, to leave the house and his family. Fortunately, the wife went with him and left her father's family. Stigma is a big factor in the big number of defaulters. Patients do not want to go to the health centers in order to avoid discrimination of the patients and their families. Combating stigma and ensuring early diagnosis through active early case-finding is critical to making progress. In order to sustain leprosy services and eradicate leprosy, people's organizations

DR. ARTURO C. CUNANAN, JR. is a member of the World Health Organization (WHO) Local Leprosy Program; of the MLCP Technical working group of the Philippines and of the Research Review Committee of the Leonard Wood Center for Leprosy Research. His other official posts include: Consultant of the Pacific Leprosy Foundation working at the Pacific Islands of Kiribati, Samoa, and Solomon Island and Visiting professor of Fiji National University. He is an advocate of the preservation of leprosy history and heritage is the current Medical Center Chief 1 of the Culion Sanitorium & General Hospital.

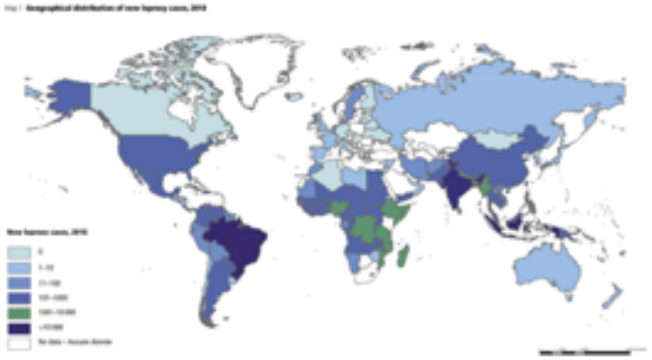
have to address stigma and discrimination in their respective countries.

In 1991, a WHO Resolution was passed to eliminate leprosy by year 2000 and at the national level in 2005. Elimination is defined as a prevalence rate of less than 1 case per 10,000 population. WHO set 2020 as the target year for the global elimination of the disease. In terms of treatment, thanks to the Sasakawa Health Foundation, patients have been provided multi-drug therapy (MDT) since 1982. The WHO strategy on MDT had simplified the diagnosis in the field implementation of the Leprosy Program. Patients were classified either as MB meaning Multibacillary or PB, which stands for Paucibacillary. This simplified classification allowed the participation of people's organizations on Hansen's disease or the people affected themselves to easily join the leprosy services or participate in the case finding or referral activities.

Where are we now?

Based on the 2018 WER report, the global map shows the countries with leprosy. In Africa and in Southeast Asia, there are significant number of countries reporting cases. Twenty five countries, representing 93.6% of the total, reported new leprosy cases. However, this does not mean that leprosy is only present in those 25 countries. Dr. Cunanan also presented figures from the WHO and discussed the trends in the detection of new leprosy cases by region. The data indicates that as countries engage in leprosy activities, the number of new cases rises. He explained that detection of new cases is highly proportional to the leprosy activities. The figures have not changed in the last 10 years. The reality in most endemic countries is that leprosy still exists. New cases continue being detected in identified pockets within previously endemic countries. These new cases are also found in countries that have reported eliminating the disease as a public health problem

It was thought that MDT implementation will drastically bring down the new cases as prevalence is brought down then prevalence and incidence will merge. The challenge is how to bring down the new cases when the problem lies in the long gap between the appearance of lesions and the treatment. The time lag is about 2-3 years. By the time patient is treated, the other members of the household have been infected by the disease. The goal is to cut the transmission and find the cases at the earliest possible time. New leprosy cases that are detected late have visible disability. The data also shows that among the new cases detected there is a high proportion of children affected and of MB leprosy type. There are also cases of post-treated patients who develop severe disabilities and need care after cure. Unlike other diseases, leprosy patients can experience reactions after treatment and can suffer progressive disability even after being discharged or they can develop a new disability after treatment. Due to what is called "post-treatment reversal reactions" or relapse, people's organizations need to advocate for services after cure (or Care after Cure) through highly-centralized clinic-based leprosy services or centrally treated facilities.



Afterwards, Dr. Cunanan discussed the issues in relation to the leprosy programs. First, when the national programs are not moving there is an absence of leprosy activities. As a result, peripheral programs do not move and peripheral health workers are less involved. Second, there is poor integration of services due to the limited or poor referral system. Third, once the disease is eliminated, the national programs receive lower budgets. Researches and the need for leprosy experts disappear. In fact, finding experts in leprosy is difficult. Moreover, supervision and monitoring of programs also suffer.

> *"There is less, if not an absence of advocacy or health education materials as well as an absence of a deeper or wider participation of health and non-health sectors. To prevent and eliminate the disease, there is a need to address non-health issues such as sanitation, nutrition, spaces and overcrowding."*

The Remaining Challenges

Despite the gains in attaining the WHO's goal of eliminating leprosy as a public health problem globally, there are still countries that have not yet achieved the elimination target. Leprosy still exists in endemic pockets in countries and in the Marshall Islands, Kiribati, and Micronesia. In Kiribati, 208 new cases out of the island's 160,000 population were detected in 2017. The detection rate in Kiribati, a small island, is higher than Brazil's. There is a need for a strategic plan to address the infrastructure, capacity and other problems faced by these three countries. Collaboration with government organizations, NGOs, and other civil society actors in various forms is critical.

Dr. Cunanan cited several challenges. One, in terms of leprosy services, there is a need to shift the focus from elimination to sustaining the quality of leprosy services using a Patient Centered Approach. This shift means moving from a clinic-based approach to a public health or community approach. Two, there is a need to increase the coverage of leprosy control activities to ensure that the disease burden declines in all parts of the country and to actual reduction in the burden of disability, of leprosy-related stigma, and in leprosy cases among children. While it is also important to measure burden of leprosy in children and the burden of stigma and discrimination, it is equally important to measure progress. There is need to work with social scientists in order to come up with qualitative and quantitative indicators to measure the size of the burden and the progress in reducing such burdens.

Three, the emergence and spread of Rifampicin-resistant strains of M. leprae is potentially the most serious threat to the future of leprosy control. The WHO and its partners are establishing a global surveillance system to monitor the situation. People's organizations should look into this issue as it could threaten programs in the future. Four, sustaining commitment is also another concern. Leprosy control activities will need continued technical and funding support from partners (WHO/ILEP). People's organizations must advocate to have leprosy remain within the health departments and in the public health agenda for continued leprosy services. Five, capacity building is also a huge challenge. The fast turnover of health workers require the continuous training of staff. Funding is essential since training is an expensive activity. Leprosy control activities need to be integrated into the general health-care system. To sustain the leprosy programs, knowledge and skills of health-care workers particularly in previously highly endemic areas, must be maintained.

Six, the existing referral system needs to be greatly improved. Referral networks for rehabilitation and for managing complications need to be established. However, putting up such systems is very difficult because the referral centers are far and inaccessible. The only emergency in leprosy is when patients are developing reactions or experiencing difficulties. The health centers cannot address these emergencies. Patients may complete MDT treatment but they end up being disabled. Dr. Cunanan proposed identifying referral facilities that could be integrated into the general health-care system. In this way, these services would be easily accessible to patients who need them, and the services offered in these referral facilities would remain affordable.


In photo: A mixed group of participants during one of the group work sessions.

He posed the question: Will there be a resurgence of leprosy in the future? If we will be complacent in doing case detection, the number of cases will rise. Thus, it is necessary to sustain leprosy services/programs to make them enduring. He shared that his dictum is, “we need to be doing things better or to be doing better things."

Where are we going?

The goal is to further reduce the global and local leprosy burden. This means (i) zero children with leprosy-affected disabilities; (ii) reduction of new patients diagnosed with leprosy-related deformities to less than one per million population; (iii) repeal of all laws that allow discrimination of leprosy patients. The strategy has to be built on three major pillars: (a) strengthening government ownership and partnerships; (b) stopping leprosy and its complications; and (c) stopping discrimination and promoting inclusion.

Strengthening the efforts to stop the transmission of leprosy should include addressing the social and economic determinants of health. These include access to good sanitation, clean water, education, proper nutrition and housing. He related that in Norway, leprosy went down even without treatment with the increase in capita income.

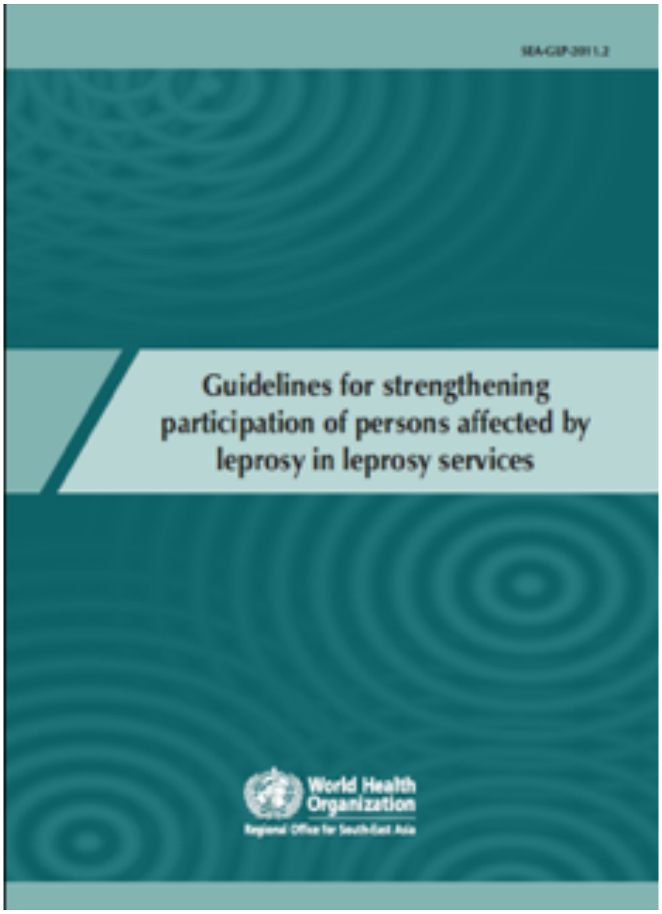
> *There is a need for better collaboration and engagement with government and other stakeholders to include civil society, academe, religious and other community stakeholders to stop transmission as well as to address advocacy, research, and non-health determinants.*

New Developments

In terms of treatment, there is a move to prevent the disease through leprosy chemoprophylaxis. The WHO is encouraging its inclusion in national leprosy programs. Based on certain assumptions, there is a strong evidence that leprosy Post-Exposure Prophylaxis (PEP MDT Plus) can reduce incidence and thereby, transmission of the infection by about 60 - 70%. Recent field studies has also shown that chemoprophylaxis with Single Dose Rifampicin (SDR) is safe and operationally feasible. PEP-MDT Plus could be integrated in routine case findings. Moreover, in some countries, the WHO plans to come up with a "mass-drug-administration" (MDA). Leprosy could learn from the MDA of Filariasis and of Trachoma, which are administered in a population-based approach.

The WHO has recommended the use of a 3-drug regimen comprising of rifampicin, dapsone, and clofazimine for all leprosy patients. The duration of treatment for PB Leprosy is six months while for MB leprosy, administration of the drugs is for 12 months. This new mode has greatly simplified the treatment for both forms of the disease.

Another development is the empowerment of persons affected by leprosy. In 2010, the WHO issued the "Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services." The WHO guidelines recognized the expertise of individuals who have been affected by the disease and provided for the enabling of these individuals to support the delivery of leprosy services through partnerships. People's organizations on Hansen's disease and patients affected themselves are the experts in detecting cases and referring people affected by leprosy as well as in ensuring patients' compliance and in advocacy, and even in case detection. Many of the people's organizations present in the Global Forum are already engaged in these activities.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Guidelines for strengthening participation of persons affected by leprosy in leprosy services

World Health Organization
Regional Office for South-East Asia

However, there are two barriers to the participation of persons affected by leprosy in leprosy services. The first barrier are the health workers themselves. Many still believe that people affected by leprosy cannot participate effectively. They do not know how to include or do not want to include the people affected by leprosy. The second obstacle is the persons affected by leprosy who are not convinced that they should participate. They do not know how they can participate or they do not want to be involved. With these words, Dr. Cunanan thanked everyone for their kind attention to his lecture.

In photo: ENAPAL representatives with Dr. Nanri

WORKSHOP

Guide questions:

1. List 5 issues and concerns in leprosy services that you are experiencing in your country
2. Is your organization participating in leprosy services?
   - ◊ If yes, what are the areas or activities in leprosy services in which your organization is participating? How?
   - ◊ If no, why is your organization not participating?
3. List 5 issues/challenges that your organization has identified or had experienced in participating in leprosy services?
4. How did your organization address or plan to address the above-identified issues and concerns?
5. How will your organization sustain the participation in leprosy services?
6. What should be the role of:
   - ◊ Partners' Organizations
   - ◊ National Leprosy Program

   in the participation of your organization in in leprosy services?

SUMMARY OF WORKSHOP RESULTS

Leprosy Services: Issues and Concerns

In the different countries, people's organizations faced issues mainly in connection to health workers, health services, and a variety of other issues related to the people affected by the disease.

A. Health workers

There is a high turnover of staff or lack of professional health workers. New doctors are not interested in Hansen's disease. They noted a lack of commitment and even negative attitudes or lack of acceptance from health providers or associations connected with provision of leprosy services. There were also cases where health providers lacked knowledge about leprosy and were the source of stigma and discrimination.

B. Health services

When it comes to the actual services, a number of the groups testified the difficulty of access to medicines and health services (e.g. rehabilitation and psychological support). Health facilities and drugs are very limited due to the minimal budget allocated. There is no "care after cure"/disability services offered and definition of treatment does not include provision of orthopaedic assistive devices. The groups noted the lack of active detection of new cases and the emergence of cases of leprosy among children.

C. Others

People affected by Hansen's disease are not included in the planning process. On their part, persons with the disease lacked mobility and thus, hesitate in participating in leprosy services. Due to stigma, they have difficulty integrating with other groups/people with disability. Group 4 related that the health system was more interested in statistical data than in the social stigma of leprosy. It also pointed to the lag time between diagnosis and treatment as a result of local beliefs and culture.

Participation of POs in Leprosy Services

All the groups reported that they are participating in leprosy services in their countries. Their participation included the following:

a. Providing capacity building, technical support, training & education, livelihood, peer counselling & motivation, physical rehabilitation, and funding
b. Providing assistance for people to access their social security benefits
c. Participating in household follow-up visits/ contact tracing or in community screening of new cases/early case detection and diagnosis / referrals
d. Organising self-care groups/programs
e. Advocacy based on family, community, schools, at the local & national levels as well as advocating for the inclusion of leprosy education in the curriculum/promote youth awareness about the disease

Issues and Challenges in Participation in Leprosy Services

Most of the issues and challenges that the organizations identified or had experienced in participating in leprosy services were similar to the first question. These included the lack of capacity (e.g. expertise/education/knowledge about national health norms, rights of peoples and families), and the lack of financial (i.e. organization and government) or and other resources such as manpower/volunteers/health experts. The groups also referred to the negative attitudes of health worker and even of former leprosy patients toward participation of Hansen's disease patients in leprosy control services. Some people do not want to be associated with the disease or are not interested in participating in leprosy services. Another challenge was how to collaborate with government and the existence of certain policies.

Addressing the Issues and Concerns

The people's organizations think they could address the issues and concerns that they identified by: First, putting the people affected by the disease at the center, driving the programs, policies and services as a way of sustaining active participation or greater involvement. They plan to enlist the younger generation in the leprosy field. They also plan to embark on capacitating the members of organization in communicating, advocating with government and philanthropic organizations. Second, through networking and collaboration, and by establishing strong engagement and partnerships with government organizations, NGOs, INGOs, and other stakeholders that are into leprosy services (e.g. media, academe, religious groups). Lastly, they plan to diversify their funding sources by studying the local sources and looking into providing transportation facilities to facilitate those mobility challenges.

How to Sustain Participation in Leprosy Services

People's organizations could sustain their participation in leprosy services by strengthening their own organizations through effective governance, regular upgrading of members' capacities, and adopting new approaches to be financially sustainable (e.g. engaging in social enterprises). The groups suggested reinforcing self-help care groups and contact tracing, doing continuous advocacy, bolstering partnerships with government and NGOs engaged in leprosy services, establishing MOU with health centers or linking health facilities, educating health and government workers about leprosy and recommending the inclusion of proper and correct knowledge on leprosy in school. Finally, they recommend mapping the process or evaluating these initiatives to check their effectiveness.

Roles of Partners' Organizations & National Leprosy Program

A. People's Organizations – provide technical (e.g. capacity building), financial support (i.e. grants, travel support) and other resources such as people to support the existing health resources and strategies, to help monitor, to strengthen the implementation of laws as well as employment/job opportunities to persons affected by Hansen's disease. Lastly, POs could encourage the sharing of ideas, establish common goals and interests, and collaborate in leprosy campaigns to direct the government's attention to the problems of leprosy patients.

B. National Leprosy Programs – could provide budget, facilities/infrastructure, and invest in capacity building to improve leprosy services. These national programs could support and recognize the initiatives of people's organizations to improve information about leprosy in the community; (e.g. in Philippines, CLAP is part of National Leprosy Control Program). They could also include persons affected by leprosy in policymaking.

FEEDBACK FROM DR. CUNANAN:

Dr. Cunanan stressed that leprosy services need to be sustained. He explained that participation of people's organizations in leprosy services is like an engagement. Organizations must be (i) willing to participate; (ii) available to participate; (iv) capable of participating and (v) committed to participate. On the part of peoples' organizations, the issues are volunteerism and time. However, since it is an engagement, the national program should also be willing to accept and facilitate the people's organizations' participation into the program. Many of the groups mentioned inclusiveness from planning to implementation.

The other issues are policy-related. There is a need to advocate for the participation of people's organizations in policies. The WHO guidelines stated that people's organizations can and should participate. It is up to the people's organizations to be engaged. It is a partnership. Drugs and health infrastructure are another set of issues. Health facilities should match the population and service. In certain geographical areas, there is a mismatch between the facilities and the people. These concerns need to be raised at the national program. The lack of human resources and the capacity for leprosy services were also mentioned. There is also the question of attitudes and behaviours of the human resources. One of the reasons patients do not finish their medicines or comply with the treatment is due to the attitudes and behavior of health workers.

In photos: (left) Active discussion during group work; (right) Group presentation

People's organizations are willing, committed and capable but like a car without fuel cannot run without a budget. The last issue is capacity. One cannot give what one does not have. There is a need for a paradigm shift. Persons affected by leprosy needs to shift from being a recipient of care to being a provider of care. In terms of research, persons affected by leprosy are no longer the subject or object of research but are now partners in research. All these form part of the essence of participation in leprosy services.

In sum, the group needs to sustain these initiatives. Dr. Cunanan liked the idea of mapping and monitoring the participation of people's organizations and checking if they are effective. People's organizations have the willingness and commitment. However, volunteers lack the capacity and training. Hence, partner organizations and national leprosy programs have to provide the necessary technical and funding support. Sustaining volunteerism and the initiatives of people's organizations are crucial because strengthening participation in leprosy services does not end in one or two years. If we are to address the remaining challenges in leprosy services in the different countries, it needs a continuous engagement.

QUESTIONS & SHARING

1. Mr. Pramod Jha of Nepal: He asked for the slide on the global incidence of leprosy shown once more. Based on the Nepal data, incidence has gone down from below 1 per 10,000 population for the whole of Nepal. However, there are 8 areas in the central part of Nepal, along the border of India, where the incidence is more than 2 per 10,000 and others even more. The challenge of leprosy remains.

Dr. Cunanan: You need to look at the country indicators beyond prevalence of leprosy because this indicator is not sensitive in terms of transmission and other activities. This indicator also cannot be related to the absolute number of cases. Prevalence is influenced by the population especially at the national level. There is also a need to look at the regional and provincial data. The WHO is moving away from looking at absolute number of cases. The data I showed is sensitive to the number of activities that you are providing. The moment you engage in more activities then the number of cases increases. I think the people's organization can get involved and help in the national programs. Budget for active case finding is usually very limited and is very expensive.

2. Ms. Paula Brandao from Brazil: I will not ask a question but to give some comments. What participating means for us people affected by Hansen's disease? What kind of participation by those affected by Hansen's disease? Who will define what that participation means: us, those affected, or the health workers? I am a person affected by Hansen's disease but I am also a health worker. The same point goes to the issue of terminology: Who will decide on the issue of how we should be called?: as lepers or people affected by Hansen's disease? Is it us or them? Finally, we should also keep in mind what is our role in this forum of people affected by Hansen's disease since it is related with the kind of participation we want for the present and for the future. We need to keep in mind these questions. What kind of participation we want in this congress or in the health services? Are we going to ask to participate or shape how we participate? Once we go back to our countries, we have a mission. We need to engage more people with Hansen's disease to work with us. It is us who have to shape in health services or state how, where and who should participate.

Dr. Cunanan: The last guideline was written in 2010. Many organizations have been participating in ways they understand and ways they can. My strong recommendation is for WHO or ILEP to look into this since people's organization have been engaged or are participating already. We need to propose that programs or WHO should review where we are now in this participation and how it could be improved. In some areas, it should be recognized that people affected by leprosy can play a major role in leprosy services. The way, how, the depth would depend on the people's organizations themselves. However, there must be a venue to discuss the ways forward. Thank you!

GLOBAL APPEAL

The Global Appeal: An Overview

MS. KIYOMI TAKAHASHI

Program Director, Sasakawa Health Foundation

SHF Program Director Ms. Kiyomi Takahashi greeted everyone “Mabuhay”. Since 2006, The Nippon Foundation (TNF), SHF's sister foundation, has been organizing the Global Appeal as one of its worldwide programs in partnership with different stakeholders.

The Global Appeal is a ceremony to raise awareness about Hansen's disease and calls for an end to the stigma and discrimination that persons affected by the disease continue to face. It is held every January in conjunction with World Leprosy Day. At the end of the ceremony, the declaration is signed by representatives of the various organizations endorsing it. The Disabled People's International, an international NGO has pledged to work together with persons affected by Hansen's disease to encourage proper treatment of the disease. Since the first Global Appeal in 2006, several world leaders, groups and individuals have endorsed it.

The next Global Appeal will be held in Tokyo, Japan on January 27, 2020 in collaboration with the Paralympic Committee. The year 2020 is the Olympic and Paralympic year in Japan. SHF believes that organizing this event with the Paralympic committee will have a great impact on society. She requested the participants for their collaboration in the production of a video with the messages they would like to share during the Global Appeal. She hoped that among those messages would be how to end the stigma and discrimination against Hansen's disease.

Ms. Kiyomi Takahashi

Global Appeal 2018

To End Stigma and Discrimination Against Persons Affected by Leprosy

Sample Declaration at the Global Appeal 2018 endorsed by Disabled People's International

Program for Global Appeal 2020

- 5 min: A short film
- 15 min: Remarks by Organizers
- 30 min: Remarks by Special Guests
- 10 min: Launch of Global Appeal 2020
- 10 min: Video Message from People's Organizations
- 10 min: Musical Performance

JOINT CAMPAIGN ON WORLD LEPROSY DAY 2020

WORLD LEPROSY DAY 2020

MS. CHIKAKO MASUZAKI

Chief Program Officer, Sasakawa Health Foundation

SHF's Chief Program Officer Ms. Chikako Masuzaki expounded on the celebration of World Leprosy Day (WLD) in 2020. Three regional assemblies were held early this year: in Addis Ababa, Ethiopia in Africa; in Manila, Philippines and in Rio de Janeiro, Brazil in Latin America, she began. Colleagues at the African regional assembly suggested to have a joint action on WLD 2020. SHF had considered all the comments coming from the regional assemblies. One of SHF's proposal was for the group to have the same logo for WLD 2020. This would be one way of showing unity and bring more impact to the WLD Campaign. "Our voices will be heard more," she said. It would also be a way of indicating that the various groups are fighting for the same issues or the same challenges.

Logo Ideas

SHF considered all the suggestions and came up with three logo proposals for World Leprosy Day in January 2020. The participants were asked to vote on the logo they prefer to use on WLD 2020.

Mr. Artur Custodio presented Logo D and its meaning. The logo was created by the same volunteer from Sao Paulo, Brazil, who made the logo of the Global Forum. He also proposed the idea of using arm bands that was inspired by Nike's campaign "stand up, speak up". These armbands could be used for fundraising.

Ms. Chikako Masuzaki

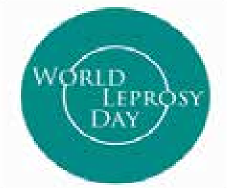
World Leprosy Day Special Grant

Aside from having the same logo, SHF would also be giving a special grant in the amount of US $3,000 with the objective of supporting the initiatives and joint action of one people's organization. The contract period would be four months, from November 2019 to February 2020, and the contract requires the following:

- Use of the logo
- Upload the organization's activity photos through SNS (at least 20 times)
- Covered by local newspaper/TV
- Three interview videos

Ms. Chikako Masuzaki encouraged all the people's organizations to apply for the Special Grant by applying for the grant.

Logo A shows bright lights like diamonds. These represent the internal light of the human being. When organizations work together they form a strong network similar to the lighted diamonds that are connected with each other.



Logo B shows two circles. The inner circle represents what one person can do while the big circle represents what organizations can do when they work together. They could reach more people and the circle gets bigger.

Logo C shows a bright light and represents the correct information on Hansen's disease. This light expands to the world and reaches many more through the joint actions.

Logo D features two hands shaking hands as a symbol of unity and respect. In addition to this gesture, in my journey as a volunteer against this disease, I could understand the symbolism of the hands since the lesions appear first in extremities of the body. Touch represents affection and affection also serves as a reminder that after treatment the disease is no longer transmissible. It signifies that the person needs attention and care and should not be excluded. "Together against Hansen's disease."

OPEN FORUM

1. **Ms. Jayashree Kunju:** Thank you Chikako! There are other people and groups that represent other NGOs. If she is part of several NGOs and was to recommend the logo these other groups, how would the logo be used and would the organization's own logo also appear?

Ms. Chikako Masuzaki: If an organization has their own logo for WLD, it could be added to the common logo.

Dr. Nanri: It is alright for organizations to use the common logo for the Global Appeal that would be chosen and to use their own logos as well.

2. **Mr. Artur Custodio:** We have discussed with the organizations that form part of Morhan about a common logo. We have created a logo for Hansen's disease not for Morhan alone. The logo is two hands holding a heart. This discussion that would unite our organizations around the world is very important. I think it is alright for our other organizations to add this logo. In Brazil, we have prepared a logo proposal. Could we show it here as this is also important for fundraising?

3. **Mr. Kofi Nyako:** The logo is not a problem. In the WLD, from my experience and what I have seen, the real problem is understanding the correct term and how to make the general public understand that leprosy is curable. Treatment is free. I think the logo of C should be modified such that when people look at it they will know what it means.

4. **Mr. Paulus Manek:** Firstly, I want to ask what term will be used: Hansen's disease or Leprosy? Secondly, could the light be made in such a way that the meaning that leprosy is curable is clearer as Kofi has suggested? The group could come up with an international slogan for WLD.

Ms. Chikako Masuzaki: The group needs to decide on what term to use: Hansen's disease or leprosy since it is your campaign. Second point, about the slogan, I think each country has different powerful words. Each country could write their own message, which the groups could discuss. We could talk about the message you want to transmit on WLD 2020.

5. **Mr. Amal Timalsina:** Good morning and thank you Chikako for your wonderful presentation. I thanked my African colleagues for bringing up these very important issues. I think everyone is excited about this. If we are united, there is power. If we celebrate globally, it will be very important. I salute you! I think that if we are able to invite one influential person from the big countries (e.g. a health minister) during the WLD, these people could bring the message to their respective countries.

In photo: Representatives of the various groups endorsing the Global Appeal held in Tokyo, Japan in 2016.

6. **Dr. Marco Frade:** Not so many people know that I was treated for Hansen's disease 10 years ago. In order to fight against discrimination and stigma, we need to work not only with our peers but also with children. I found the proposed logos very interesting but afraid that they are quite complex but those to whom the message is directed may not get it. We could only end discrimination and stigma if we work with children. I think we should try to think more of how to make the logos more attractive to and more colourful children. and in this way catch their attention and we would not have such a big problem with stigma and discrimination.

7. **Mr. Artur Custodio:** I just want to make a comment to Marco's suggestion. I agree with him partially. Our logo will never be able to say everything we want to say. What will make the difference is where and how the logos are going to be used. It could be used in toys, for example. The logo itself does not say everything. How it will be used and what meaning will be added. Coca Cola's logo does not say everything but we all know what the logo means and we look for it. What we should discuss now is the four logos presented.

8. **Mr. Paulus Manek:** I am more interested in Morhan'S proposed logo because of the symbol of being touched and the message of acceptance for people with leprosy. That is the important message.

9. **Mr. Isaias Weck:** Good morning everyone! I loved the idea from our African colleagues because it seeks union, joint work. The concept of the WLD, for all of that have had Hansen's disease, reminds us to overcome this disease. One of the things that usually gathers people is music. In my country, there is a song that gathers people and raises awareness about the disease. If there is time, we could share this song. We have versions in Spanish and English. We could adapt it and localize it for countries and make a single voice around the world.

10. **Ms. Lucrecia Acevedo**: Music is important since it reaches all people with a clear language. It is very important that we convey clear, understandable message considering the differences in educational levels. It is very clear that in the community of people affected by Hansen's disease or leprosy that we lacked scientific research. We need to formally investigate these issues. I call upon all scientific workers and health workers in this area to come up with a terminology that makes it understandable for everyone.

11. **Mr. Kofi Nyako:** I think we are still discussing the grant. In order not to waste a time, I think each one has to look at their local situation and apply for the grant. Each organization can develop their proposals on what they could do in their own countries.

Dr. Nanri: The grant has very specific demands on how it is to be used. The minimum set of activities to demonstrate the unity of the group. If you agree, I leave it to you how to use the grant. It may not be feasible to have one or common activity but we can agree on the concept. The grant is quite flexible for organizations to do or organise what they want to do for WLD 2020. It is friendly for grantees.

12. **Mr. Joshua Mamane:** Today, we are talking about what unites us. The basic issue is to make a change that everyone understands. Let us not focus on what we are looking at all the time. We need to bring in new ideas. Perhaps, shaking hands as a logo may have been used by other organizations. The new thing is what catches people's attention. That is when people usually asks questions. When I am looking at logo C, it shows our unity. This is a good opportunity to have a united voice in the group. We can have a better understanding in society to have a single logo that really expresses the unity among the community of people affected by leprosy.

In photo: A Global Forum participant gets his picture taken for a Facebook post.

Dr. Nanri summed up the discussion that everyone agrees with the concept of conducting a joint activity and using the same logo during WLD 2020. While using the same slogan is a good idea, it may be better for the organizations to have the freedom to use their own slogans in their languages. Since there were other suggestions such as changing the name from World Leprosy Day to World Hansen's Disease Day, using emblems and armbands, he invited each region to send one representative to help in drATFIng a TOR for the campaign.

SPECIAL LECTURE

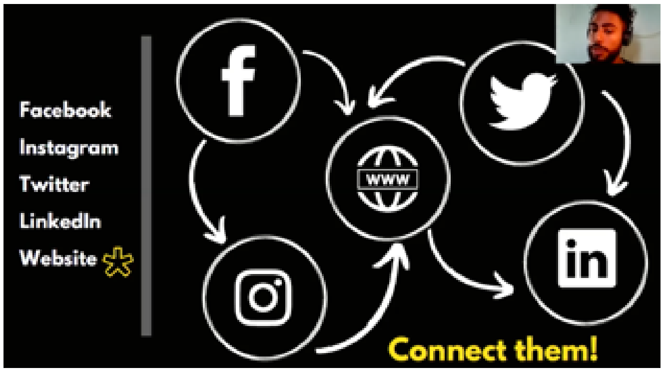
How to Use Social Network Service (SNS) Effectively

MR. MAJID SUR
Inter Press Service (IPS)

Mr. Majid Sur

Mr. Majid Sur, a journalist and analyst of Inter Press Service (IPS), shared that there are many Social Network Service (SNS) that could be used today. Facebook, Instagram, LinkedIn, and Twitter are not the only ones. He then talked about the suitability of each service. Websites and SNS differ in terms of the ownership of the content. For websites, the content shared in the website is the property of the person posting the content.

However, in SNS, the ownership of the content posted is shared by the one posting and a third party. This means that the eventual revenues, whether financial or in terms of the number of followers, are also shared. For instance, what is posted in Facebook is not entirely ours but is shared with Facebook. On the other hand, in websites, the one posting has the sole ownership of what is posted hence, the entire revenue belongs to that person.



Facebook
Instagram
Twitter
LinkedIn
Website

He emphasized the importance of having both a website and a social media account. When the internet is down, the visibility of the organization remains live. If the presence of the organization is limited only to social media and those SNS are down, then the organization is out of the market. He stressed that it is crucial for customers to reach the organization in various channels. Even for websites, sometimes when the Google search engine is down, then at least customers can reach the organization through SNS. It is also important to have SNS accounts in social media platforms that are connected to the website. By doing so, the organization is able to connect its customers to its website. This is critical when the organization is doing a marketing campaign. The key to all these is maximizing the content of both.

Social Media Campaigns

Mr. Sur explained that social media marketing is a type of internet marketing that is done through the SNS. The goal of social media marketing is to produce content that customers will share to their social media network to help a company increase brand exposure and increase customer reach. Brand refers to all aspects that characterize the organization's or company's identity on the web against its competitors. Company logo, slogan, and all the visual aspects such as color are all part of the branding.

Identifying the social media platform that the organization wants to use is the first step in social media

> *The goal of social media marketing is to produce content that customers will share to their own social media network to help a company increase brand exposure and increase customer reach.*

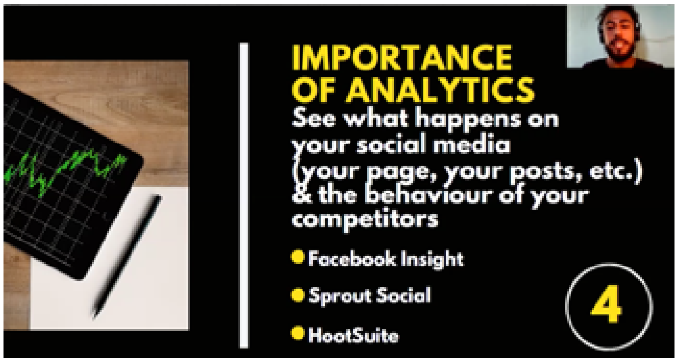
marketing. For instance, LinkedIn is a very specific social media channel that is aimed at recruitment. If the organization does not have such specific objective, then LinkedIn is not appropriate as each of the platforms have their own language and approach. Mr. Sur discussed the six initial steps in making a social media campaign.

1. **Distinguish clearly the aim of your campaigns.** Businessmen normally prioritize investments over the quality of the content. Nonetheless, both are needed in the organization's marketing activities. Investment is necessary in marketing but at the same time quality content is the core of the marketing activity. Even if the organization invests a lot of money but does not have quality content, in the long run, its marketing campaign will not be successful. In sum, investment is necessary but so is quality content.

2. **Set-up an editorial plan.** It is important to post different contents every day. Using Sasakawa Health Foundation (SHF) as an example, he proposed that on Mondays, it can post something about leprosy and what SHF does to fight leprosy. Monday posts should be light. Then on Tuesday, there should be a more in-depth analysis like an article written by an expert. Something like an explanation of what the foundation has been doing. It should be engaging for customers to read and understand. On Wednesday, the post can be something related to how the foundation was able to raise its resources. The goal should be to try to bring customers to the other channels of the foundation's network. On Thursdays, since people are getting tired, make it more infographic like where high leprosy incidences can be found around the world and how many people are affected. It should still be giving out information but more visual ones. Since people are tired on Fridays, the post should be something light and engaging. For instance, some interesting headline like a child affected by Leprosy. It should be something interesting but not very engaging. It is not advisable to produce new content on weekends because people will not be able to see it. Reposting what was posted during the week is fine as long as it is not a copy and paste work.

3. **Make a corporate video**. Mr. Sur underlined the need for an organization to have a corporate video, which could be posted easily on different media channels.

4. **Analysis is important.** SNS analytics is in-depth activity, Mr. Sur explained. If the organization has a Facebook account, it can basically see how people engage with its own page through Facebook Insights. Analytics can track the increase in followers as well as how the organization fares with its competitors. By tracking the activity of people in Facebook page, it will provide the organization with insights on how to improve its marketing campaign.



IMPORTANCE OF ANALYTICS

See what happens on your social media (your page, your posts, etc.) & the behaviour of your competitors

- Facebook Insight
- Sprout Social
- HootSuite

4

5. **Live and direct posting.** Mr. Sur discussed how these tools should be navigated even if they are limited in time. For instance, Instagram Stories stay only for 24 hours. Customers or followers know that it is only available for 24 hours. They are more powerful because people are more interested to see it before it expires. There is a huge rise in the use of these tools.

6. **Involve important actors.** This means involving important people, institutions, and companies who are active in the sector. He encouraged everyone to try to involve these actors in their posts and in their discussions. Through them the organization could reach more followers, he added. It is an indirect way of accessing a huge audience. For instance, if the organization is into climate action, and engage Leonardo di Caprio, he would help increase the campaign because he is popular and involved in climate change efforts.

More Helpful Tips

Use the company logo in the organization's profile picture in its Facebook page. It should not be changed unless there is an important change in the identity of the company. He also encouraged using videos. Use Facebook sponsorship since it is easy and inexpensive. It allows specific targeting of people according to their profile such as age, job, etc.

LinkedIn is very specific or sectorial. At the same time, he pointed out that LinkedIn is a tool used by people to know more a company. It has to be used with criteria. Important people in the organization should have a profile in LinkedIn. One could also create a profile or page about a specific project rather than posting in the organization's profile in LinkedIn.

Instagram is on the rise while Facebook users are declining. More young people use it. Instagram stories are very important in marketing campaigns. Tagging the right people provides more advantage. One can reach more people without spending more. Twitter is another very practical social media, Mr. Sur added. It is not the very best platform in communicating with other people. It's important in communicating a message. Using the right hashtags helps reach a greater number.

Before ending his lecture, Mr. Sur listed more guidelines when doing social media marketing:

1. Privacy – Be aware of the regulations affecting social media marketing in the country. Consult experts who understand regulations about privacy.

2. Copyright – Make sure you have the right to post the pictures, information, etc. Cite the authors, if necessary.

3. Communicate in English – People could use translation. However, if one is trying to reach more people, English is still the main working language.

A FEW MORE TIPS

LAST BUT NOT LEAST!

- Privacy
- Copyright
- Communicate in English
- Embrace the Visual
- Headlines Matter
- Ask Questions
- Post Multiple Times?
- Outsource to Social Media Managers

4. Embrace the visual – People get tired of reading a lot. It helps to post something more visual. Even if you want to share an article, always accompany it with a picture.

5. Headlines matter – Pictures and content are important, but headline has to be interesting and attractive since it is the first thing that customers see.

6. Ask questions – Do not just post. Ask what they think about specific topics. Read the comments on your post and you can change your way of posting based on their feedback.

7. Post multiple times – Posting multiple times should be done because not all followers are in the internet for 24 hours. It gives them the chance to see your post. Share content multiple times but make alteration in the headlines.

8. Outsource to social media managers

In photos: Participants from Latin America during the Open Forum in one of the sessions.

SUMMARY & RECOMMENDATIONS OF THE GLOBAL FORUM

The final summary and recommendations of the Global Forum that appear below was a joint effort of the members of the draft working committee and which was examined and further enhanced by the delegates during a plenary session. The members of the draft working committee were as follows: Mr. Tesfaye Tadesse (Ethiopia), Mr. Artur Custodio (Brazil), Ms. Paula Brandao (Brazil), Mr. Yohanna Abdou (Niger), Mr. Mathias Duck (Paraguay), Mr. Maman Sunarman (Indonesia), Ms. Rachna Kumari (India), Ms. Lilibeth Evarestus (Nigeria), Ms. Jennifer Quimno (Philippines), Dr. Arturo Cunanan (Philippines) and Mr. Jonathan Lloyd-Owen (Japan).

The Global Forum of People's Organizations on Hansen's Disease was held in Manila from September 7 to 10, 2019.

Organized by The Nippon Foundation and Sasakawa Health Foundation, the Global Forum brought together representatives of People's Organizations from 23 countries. Over 80 people attended, including observers and resource persons.

It followed three regional assemblies held in Africa, Asia and Latin America/Caribbean earlier this year that laid the foundations for the Global Forum and helped to shape its agenda.

The Global Forum provided a platform for People's Organizations to share plans, ideas and experiences, learn from each other, receive training aimed at strengthening their capacity, make recommendations and provide a "people's perspective" on Hansen's disease to international organizations, national governments, partner institutions, media and other stakeholders.

The title of the Global Forum took into account the concerns and recommendations from the African and Latin American/Caribbean assemblies regarding terminology and self-identification. This resulted in using the term Hansen's disease and not leprosy, and People's Organizations on Hansen's Disease rather than Organizations of Persons Affected by Leprosy.

Over four days, the Global Forum addressed a number of themes that People's Organizations have identified as important to them in terms of their organizational capacity, sustainability, and capability to meet the expectations of the people they represent.

There were training workshops on social enterprise, fundraising, management and networking. There were plenary sessions on human rights, sustainability and public health, followed in each case by group discussions. There were deliberations to organize a joint campaign for World Leprosy Day 2020.

The Global Forum underscored the fact that Hansen's disease is not just an issue of health but an issue of human rights. Efforts against Hansen's disease will not be successful if they only treat the bacterial causative agent and do not address the disease's physical, psychological, social and economic consequences.

Although the disease is curable, it is still stigmatized. The continuing stigma remains a barrier to case detection, treatment and inclusion.

The Global Forum recognized that addressing issues of clean water, nutrition, good sanitation, housing, education and dignified work—issues that go beyond health—is critical to a comprehensive strategy against the disease.

The Global Forum noted that in a time of lowered government priorities on Hansen's disease and the non-uniform distribution of cases, empowered People's Organizations on Hansen's disease are needed more than ever: to advocate for sustained Hansen's disease services that deliver accessible quality treatment and rehabilitation; and to promote dignity, equality and respect for human rights.

During the four days of discussions, participants in the Global Forum recognized that they have a responsibility not only to represent their organizations, but also all those who do not have a voice and were not present in the Global Forum.

Against this backdrop, the Global Forum came up with a number of conclusions and recommendations, as follows:

CONCLUSIONS AND RECOMMENDATIONS

Hansen's disease is more than a disease caused by a bacterium. Poverty, institutional, social and political neglect, complacency and the structural invisibility of vulnerable populations contribute to the perpetuation of Hansen's disease.

There are still gaps in knowledge about Hansen's disease. More investments are needed to research and develop new diagnostic tools and effective anti-microbial treatments and for management of Hansen's disease reactions, and to develop new models to manage social aspects of the disease. Greater commitment from government, academic institutions and industry are needed.

National programs should strengthen timely case detection, disability prevention and rehabilitation during treatment, and develop services for care after cure to include psychological, social and economic rehabilitation.

The UN Principles and Guidelines for the elimination of stigma and discrimination against persons affected by leprosy and their family members should be widely disseminated and implemented by governments and civil society.

All remaining discriminatory laws and practices must be abolished. Although that would represent important progress, it would not be enough for the enforcement of human rights, for which affirmative and reparation measures and policies are needed.

Full and impactful participation of People's Organizations in policy-making processes concerning Hansen's disease must be assured.

Special attention must be given to the situation of vulnerable populations with Hansen's disease—especially women, children, immigrants, refugees, the elderly and the homeless—and those living in geographically inaccessible areas.

Governments should develop measurable action plans recognizing that not only the health ministry, but other ministries and agencies must be involved collectively in resolving Hansen's disease issues.

People's Organizations should strengthen existing networks and create truly functioning regional and global networks. NGOs and governments should strive to support the formation and sustainability of these networks.

People's Organizations must actively advocate for quality Hansen's disease services within an integrated health structure and system and through their committed participation help ensure the sustainability of the Hansen's disease program.

Governments and other partners should be open and willing to fund projects that address the sustainability of People's Organizations in recognition of the contribution these organizations can make.

As a step toward reducing stigma and discrimination, there was strong support from some quarters of the Global Forum for the term Hansen's disease to be adopted as the official term for leprosy worldwide.

Although not on the formal agenda of the Global Forum, the participants recognized the importance of preserving Hansen's disease history and heritage as a record and a guide for future generations.

In photo: Mr. Jonathan Lloyd-Owen

CLOSING SESSION

MESSAGE FROM PARTICIPANTS

> *Thank you very much! I feel grateful, honoured to be asked to give the message at the closing of this Global Forum. We already saw the summary as well as the conclusions of this meeting. However, I also would like to share my own thoughts. From this meeting, I got a new spirit, a new passion that I could share to end the stigma and discrimination of the disease back to my country. I also saw the same spirit from a co-participant. I hope this same spirit would help to end the stigma and discrimination of the disease in each of our countries. We may not have been able to discuss all the issues during this meeting but we have many things to take home to our countries that could help in our work.*
>
> *I agree with what Mr. Yohei Sasakawa stated. We are not medical doctors but we are doctors in a different way, who could help share what may help those who are suffering from the disease. I hope we could learn from the strategies employed in other countries. For myself, I have learned from their strategies. Thank you to all the organizers, to the SHF, to all friends here, to Filipino friends with your great smile, to Jennifer. I also would like to apologize in case the way I said things. Lastly, please accept us.*
>
> ***- Mr Paulus Manek, PerMaTa Indonesia***

> *"Mabu-Mabu- hay!" We say Caribu! Personally, I want to thank the organizers of this event. It is rare to have this kind of opportunity. You may understand how I feel about this. We are here as organizations as people affected. Indeed, this was our forum and it exceeded my expectations.*
>
> *I encourage everyone to familiarize themselves with the WHO guidelines for strengthening the participation of people affected in leprosy services. That should form our creed. That is very important to us. In that document, we are the only stakeholders with a role from end to end of the whole process. We have a role in overcoming the stigma and discrimination. We have a role in disseminating positive and correct information as well as in education, communication, in advocacy. We have a role in equity, social justice, and human rights. We have a role in addressing gender issues. We have a role in offering psychological support. We have a role in training and capacity building. We have a role in referral and empowerment processes. We have a role in resource mobilization, in monitoring and evaluation of leprosy services. We are everywhere. This is specific to the African region. We have a request to some of the prospective partners present, we are requesting, as the African chapter, that you support us in organizing a smaller conference shortly after so that we could polish, review and adopt the outcomes of this important forum and also to review the progress of individual associations have made since we met last year. That would help us on how we move from this forum. Our second, we would also like to ask for support to set up a small working committee around the experiences and resourcefulness of Mr. Kofi Nyarko from Ghana. This committee will help energize the smaller national organizations and put together expertise. I am happy to report that in principle, Dr. Sunil Deepak and Dr. Cunanan have agreed to be part of the working committee. Ms. Lilibeth Evarestus, a lawyer from Nigeria, has also agreed to be part of this committee. My time is up. I cannot leave before thanking Sasakawa Health Foundation so much! Try to imagine what the leprosy program would be without Mr. Sasakawa. It looks so well with him. We need to strongly support him so that in the next few years we will be done with leprosy such that it is just a normal disease.*
>
> ***- Mr Joshua Thomas Eenos Oraga, ALM***

MESSAGE FROM MR. MIYOJI MORIMOTO IDEA Japan

In photo: Mr. & Mrs. Morimoto today

Ms. Ayako Murakami, a member of IDEA Japan read a message from IDEA Japan President Mr. Miyoji Morimoto who is unable to attend the Global Forum!

"Persons affected by Hansen's disease from around the world, thank you always for your heartfelt friendship! In 1996, the Japanese leprosy prevention law was abolished. My wife and I fought against the disease. Around that time, two events took place that I can never forget. The first was a visit to Mother Teresa's colony in India. For 10 years, a group of residents, doctors and nurses from Zenshoen Sanitarium in Japan have been sending goods and donations to that colony. In 1996, we received an invitation to visit. We went to India to meet Mother Teresa. She was delighted to see us. "You are not very rich and yet you have given us so much," she said. "A small but meaningful contribution from a poor person is more valuable than a big donation from someone with lots of money." That experience was the turning point of my life and one that I treasure. The second event that I could never forget was the encounter in IDEA Japan in 1997. Ms. Colmeiro, the International Coordinator, had noticed the work that my wife and I had published. As a result, we were invited to take part in IDEA's Quest for Dignity exhibition held at the UN headquarters in New York as representatives from Japan. During the opening ceremony, I was able to give a speech.

In photo: Miyoji Morimoto contributes funds to Mother Teresa for her work. (1996)

At the age of 14, I was diagnosed with Hansen's disease and isolated in a sanatorium. It took 10 years before I was cured. I went on to graduate from university, I never dreamed of attending and found my place in society. I got employed in a bank. Everything was going well until the disease returned. I had no choice but to return to Zenshoen. Around that time, Miyako, a student from Indonesia got sick with Hansen's disease. She was a patient with the same disease whom I met in Zenshoen. We got married. We were going to spend the rest of our lives there. The more we got involved in the activities of the association, I began to question the way I was living.

In 1996, Leprosy Prevention law was abolished after 89 years. I wrote a book about our struggles against the disease under our real names. The book became a sensation throughout Japan. My brothers and relatives were so shocked and fiercely pushed back. They said, "Don't make it harder for us than it already is." But unless they *join us in the fight against we will never take a step forward against discrimination. Those of us affected by Hansen's disease have gone through hard times. But that gave us the patience and courage to overcome any hardship. Now is the time for us to play our part for a peaceful and bright future through IDEA's international activities.*

As a result of that international gatherings organized by IDEA at the United Nations, I started having IDEA friends from around the world. I learned a lot from the various activities in their countries. I also learned from the beauty of friendship based on trust. IDEA is based on the concept of integration, dignity, unity, and economic advancement. I was determined to realise this through our international activities. The biggest issue in Japan is how to restore ties in the family. The family is the starting point of these problems. Hence, we decided to engage in awareness-raising activities such as lectures, photo exhibitions, and presentations to put an end to stigma and discrimination.

> ***Through IDEA international network we came to know about children affected by Hansen's disease living in difficult circumstances. We subsidized their educational expenses and provided funds to improve the living environment so that they could grow up to be self-reliant in the future.***

For about 20 years, I remained active at home and abroad. When Miyako and I came out 23 years ago, I did not know how to move the activities. But through warm friendship and support of you all that I am filled with so much gratitude that I cannot express it in words. We regret that we have to leave our activities in IDEA Japan. The reason for this is that in 2016, I suffered cerebral infarction and which have made it difficult for me to speak. I also broke my hip and if I have to go anywhere I need to use a wheelchair. My eyesight is gradually worsening. Each day is difficult for me. After thinking in over, I returned to Zenshoen in February this year as all our board members are growing old. We concluded that it would be difficult for us to continue our activities. That's why we decided to leave IDEA Japan. I offer you my heartfelt thanks for the friendship you have shown us."

That is Mr. Morimoto's message to you, Ms. Murakami said. Afterwards, Ms. Murakami showed photos of Mr. Morimoto and the various activities they carried out to end stigma and discrimination against those affected with Hansen's disease. Ms. Murakami ended with a wish that they could contribute to ending stigma and discrimination in the future.

In photos: (Left) Speaking at UN headquarters Took part in IDEA's Quest for Dignity exhibition and met IDEA members from around the world (1997), (Right) Touring the sanatorium / showing visitors around Zenshoen. To datel, Mr. Morimoto has made 1,270 presentations.(2010)

In photo: Dr. Nanri giving his final remarks at the close of the Global Forum.

CLOSING MESSAGE

Dr. Takahiro Nanri

I do not have much to say except thanks to everyone for your support and cooperation to make this happen. I want to congratulate all of you for having a successful forum. You are an important part of the work of the foundation. I also want to thank the resource persons and all the facilitators for the different group sessions. You should also join us in thanking our host organization, our friends from CLAP Philippines. I should not forget to thank Inter Press Service for their innovations in the use of social media. I also want to thank JTB Travels which took care of all the logistics.

Last but not the least, I thanked my team in SHF in preparing for this conference for the last few months and they did a great job. And, I hope you do not mind my mentioning the name of each of my team. Chiemi is the head of Communications and Grants Management System. Chihiro is taking care of the communications of the foundation. Chikako is the Chief Program Officer who taking care of some countries in Africa and in Asia like Bangladesh, Indonesia and Philippines. She is an important person for you. Kenshi works with Chikako. I also want to thank Kiyomi although she is not here. She is the Program Director of the foundation in charge of most priority countries like India and Brazil. She is also in charge of other countries like Myanmar.

Before concluding my remarks, you may recall that in my message on the first day I said 80% of our work in the foundation was over. I did not tell you what composed the 20%. What makes up the 20%? You did a great job in the last four days. It was very inspiring for all of us. It is our duty to consider what we can do after this. Our resources are limited but we should do our best on how we can respond to your demands. As Joseph said, you also have an assignment but we as a foundation also have our assignment.

Again, thank you very much for all your support and cooperation. Mabuhay!

Logo for WHDD 2020

SHF had a discussion with representatives from each region and the designer incorporated their comments in the logo's design. Below is the final design of the logo that will be used for World Hansen's Disease Day in 2020.

LIST OF PARTICIPATING PEOPLE'S ORGANIZATIONS

Country	Name of Organization	Supporting Organization
Bangladesh	Bogra District Leprosy & Disability Development Organization	Lepra Bangladesh
Bangladesh	Disadvantaged People's Association (DAPA)	TLMI-B
Brazil	Morhan	
China	HANDA	
Colombia	Felehansen	
DRC	OPALCO (Organization of People Affected by Leprosy in Congo)/IDEA Congo	
Ethiopia	ENAPAL (Ethiopian National Association of Persons Affected by Leprosy)	
Ghana	IDEA Ghana	
India	APAL (Association of People Affected by Leprosy)	
India	Children United for Action	TLM Trust India
India	Samuthhan	Lepra India
India	IDEA India	
Indonesia	PerMaTa Indonesia	
Kenya	IDEA Kenya	
Mozambique	IDEA Mozambique	
Myanmar	MAPAL (Myanmar Association of Persons Affected by Leprosy)	TLM Myanmar
Nepal	IDEA Nepal	
Niger	IDEA Niger	TLM Niger
Nigeria	IDEA Nigeria	
Philippines	CLAP	
Philippines	IDEA Philippines	
Sri Lank	IDEA Sri Lanka	
Tanzania	TLA (Tanzania Leprosy Association)	

PROGRAM

GLOBAL FORUM OF PEOPLE'S ORGANIZATIONS ON HANSEN'S DISEASE

Master of Ceremonies: Ms. Jennifer Quimno (CLAP)

DAY 1	**Saturday - September 7, 2019**
8:00-9:00	Registration
9:00-10:00	Opening Session
	Prayer and National Anthem: CLAP
	"Welcome Message & Introduction of Participants: Dr. Arturo C. Cunanan, Jr., Medical Center Chief I, Culion Sanitarium and General Hospital"
	Key Note Speaker: Dr. Maria Francia M. Laxamana, Assistant Secretary, DOH
	Message: Dr Huong Thi Giang Tran - WHO Western Pacific Regional Office
	TNF/SHF Message: Dr. Takahiro Nanri - Executive Director, Sasakawa Health Foundation, Japan
10:00-10:30	Group photo / Coffee break
10:30-12:00	Results of the Regional Assemblies
	Africa: Mr. Tesfaye Tadesse, Managing Director, ENAPAL, Ethiopia
	Asia: Mr. Francisco Onde, Chairman, CLAP, Philippines
	South America: Mr. Faustino Pinto, Morhan, Brazil
12:00-13:00	Lunch
13:00-15:00	Training Workshop 1: Social Business/Fundraising/Management
	Resource person: Mr. Earl Parreno, the Chairperson of Alter Trade Foundation Inc (ATFI)
	(1) Lecture
	(2) Questions & sharing of experiences from the participants
	(3) Groupwork (small group discussions)
	(4) Presentation from groups
15:00-15:30	Coffee break
15:30-17:30	Training Workshop 2: Networking and Volunteers
	Resource person: Mr. Artur Custodio , Morhan, Brazil Mr. Faustino Pinto, Morhan, Brazil
	(1) Lecture
	(2) Groupwork
DAY 2	**Sunday - September 8, 2019**
8:30-9:00	Registration
9:00-12:00	Human Rights Session
	Resource person: Ms. Alice Cruz, UN Special Rapporteur
	(1) Lecture on current challenges and issues on Human Rights
	(2) Report on Japanese Lawsuit (Dr. Ai Kurosaka, Japan)
	(3) Group discussion
	(4) Sharing the results of group discussion & coming up with recommendations
12:00-13:00	Lunch
13:00-15:00	Sustainability Session
	Resource person: Dr. Marie Lisa M. Dacanay, Institute for Social Entrepreneurship in Asia
	(1) Lecture on Social Business, Marketing, Fundraising
	(2) Group discussion
	(3) Sharing the result of Group discussions & coming up with recommendations
19:00-20:30	Informal session

DAY3 **Monday - September 9, 2019**

8:30-9:00	Registration
9:00-10:00	Keynote Speech
	Mr. Yohei Sasakawa, Chairman, The Nippon Foundation/WHO Goodwill Ambassador
10:00-10:30	Photo / Coffee break
10:30-12:30	Public Health
	Resource Person: Dr. Arturo C. Cunanan, Jr.
	(1) Lecture on Public Health
	(2) Group discussion
	(3) Sharing the result of Group discussions & coming up with recommendations
12:30-13:30	Lunch
13:30-17:00	City Tour
19:00-20:30	Dinner hosted by Mr. Sasakawa, Chairman of TNF/WHO Goodwill Ambassador

DAY 4 **Tuesday - September 10, 2019**

8:00-9:00	Registration
9:00-12:00	Global Appeal & Joint Campaign on World Leprosy Day 2020 - TNF & SHF
	History and Concept of Global Appeal - Ms. Kiyomi Takahashi
	Joint Campaign on World Leprosy Day 2020 - Ms. Chikako Masuzaki
	Lecture: How to use SNS effectively - Mr. Majid Sur, Inter Press Service (IPS)
12:00-13:00	Lunch
13:00-14:00	Summary and Recommendations of Global Forum - Ms. Jennifer Quimno & Dr. Cunanan
14:00-15:00	Summary for Official Workshop - Dr. Nanri & Mr. Tesfaye Tadesse
15:00-15:30	Closing Session
	Message - Mr. Paulus Manek, PerMaTa Indonesia
	Message from Mr. Miyoji Morimoto, IDEA Japan - Ms. Ayako Murakami
	Message - Dr. Takahiro Nanri, Sasakawa Health Foundation
19:00-20:30	Informal Session

DAY 5 **Wednesday - September 11, 2019**

8:30	Registration at ILC
	ILC Opening program
	Lunch
16:15-18:00	Workshop @ ILC Official Event
	Chair: Dr. Takahiro Nanri, Co-chair: Mr. Tesfaye Tadesse
	Human Rights - Mr. Faustino Pinto, Morhan, Brazil
	Sustainability - Mr. Wu, President, HANDA, China
	Public Health - Mr. Bekele Yemiru, ENAPAL, Ethiopia

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