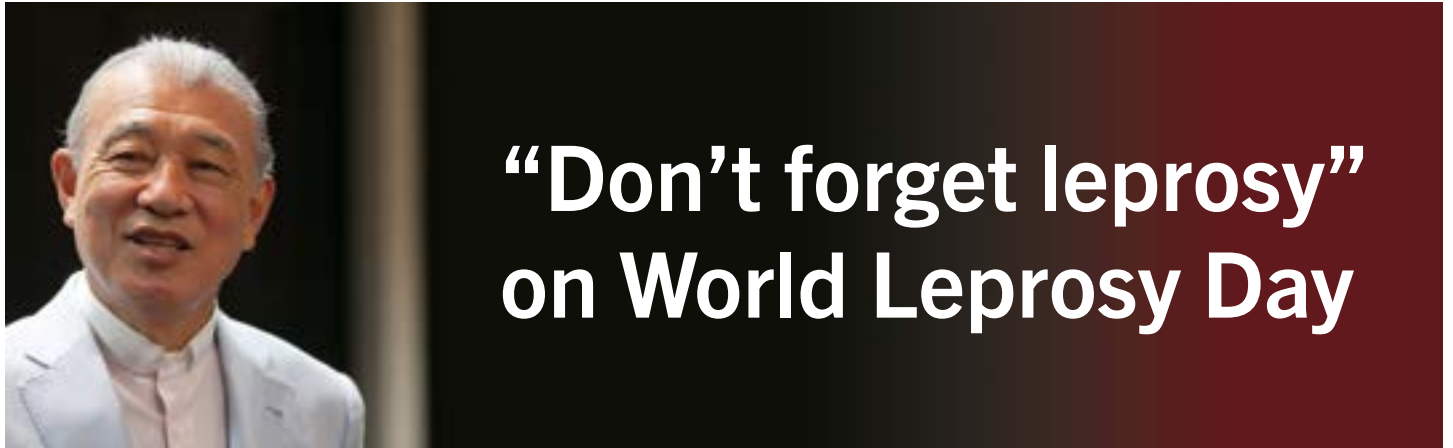


LEPROSY BULLETIN

NO. 107 JANUARY 2022



Message from the ambassador

In August 2021, I launched an awareness campaign called "Don't forget leprosy." The slogan is meant to be a reminder that persons affected by leprosy and their families continue to experience stigma and discrimination, and measures to prevent the spread of COVID-19 have made their lives even more difficult. I also want to encourage support for medical professionals who continue to work hard to treat patients under challenging conditions. I hope that everyone worldwide will join this campaign and speak up from wherever they stand to say that leprosy must not be forgotten.

I have sent letters to the health ministers of 56 countries reminding them of World Leprosy Day on Jan. 30 and asking for their cooperation with this campaign. People's organizations and NGOs from 16 countries have joined a campaign-related grant program that supports awareness-raising activities and surveys of the situations of persons affected by leprosy and their families. This year, the Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, an annual event that I initiated with the support of The Nippon Foundation in 2006, is thematically linked to the campaign.

The primary reason that I launched the Global Appeal was to broaden the scope of our awareness-raising activities; in other words, to communicate the reality of discrimination to those who were not yet aware of the issue. Over the past 16 years, the Global Appeal has been the catalyst for new relationships with people in a wide variety of fields, including medicine, law, government, and business. This year, we focused on connecting with philanthropic foundations. I continue to believe that together we can end stigma and discrimination.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Prof. Muhammad Yunus
2006 Nobel Peace Prize Laureate

Paula Brandão
Morhan Research Center, Brazil

Patricia Soares
DPW-Morhan, Brazil

Francilene Mesquita
DPW-Morhan, Brazil

Suerli Oscar
DPW-Morhan, Brazil

Nanda Duarte
Morhan, Brazil

Maksuda Khatun
Sirajganj, Bangladesh

Dr. Michael Chen
HANDA, China

LEPROSY IS CURABLE. MEDICATION IS FREE. STOP DISCRIMINATION NOW.

INTERVIEW



Professor Muhammad Yunus

2006 Nobel Peace Prize Laureate and founder of Grameen Bank

Yunus Centre

The Yunus Centre strives to engage individuals and organizations in creating, promoting, and maintaining social business by spreading the concept through workshops, internships, and projects.

<https://www.muhammadyunus.org>

Change the system rather than looking for solutions within the system

Based on the idea that “the poor themselves can create a poverty-free world” as long as we “free them from the chains that we have put around them,” Professor Muhammad Yunus developed a system of “microcredit” that gives very small collateral-free business loans to society’s poorest people. He institutionalized this system in Bangladesh with the Grameen Bank. Since its establishment in 1983, the Grameen Bank has provided US\$6.5 billion in collateral-free loans to 7.5 million clients in more than 82,000 villages in Bangladesh, with women making up 97% of its loan recipients. In 2006, Professor Yunus and the Grameen Bank were jointly awarded the Nobel Peace Prize “for their efforts to create economic and social development from below.”

On the occasion of the 2015 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, Professor Yunus sent a message in which he said it is essential that every possible means is used to create awareness of the disease.

The COVID-19 pandemic, which began affecting most countries in 2020, has made sustaining awareness of leprosy more difficult. At the same time, the social and economic impact of the pandemic has hit vulnerable communities of persons affected by leprosy particularly hard, which makes awareness-raising more important than ever.

In this context, and with the 2022 Global Appeal happening this month, the Leprosy Bulletin returned to Professor Yunus for an interview.

LB (*Leprosy Bulletin*): With the world in the continuing grip of the COVID-19 pandemic, other diseases tend to receive less attention. How would you frame discussion so that leprosy-related issues continue to be addressed?

Professor Yunus: The COVID-19 pandemic has created an excellent context for talking about the fundamental issue of healthcare. The issue is the inadequacy of healthcare in almost all countries. The pandemic has brought out very clearly how inadequate the public health system is globally. It has shown how profit-maximizing pharmaceutical companies remain busy with their profit calculation rather than saving the lives of people. Lack of frontline workers in the health sector is another basic problem. It is not equipped to deal with an emergency situation.

Leprosy is one disease which highlights the unpreparedness of the healthcare system. While we should encourage everybody to work dedicatedly for any particular disease, like Mr. Sasakawa does for leprosy, we must not forget to focus on each disease within the framework of a total

healthcare system. We cannot succeed in one disease while ignoring the others.

We must aim for a systemic solution. No disease is less important than any other. They are interlinked.

LB: Leprosy is a disease that is closely related to poverty. What can be done to help people escape poverty?

Professor Yunus: The best way to help people overcome poverty is to treat each person as an entrepreneur. All human beings are born as potential entrepreneurs. But our wrong economic thinking turns them into job-seekers, and then society fails to provide decent jobs for everybody. This creates poverty. We must create a new financial system that can guarantee finance for every single person to become an entrepreneur. Our present banking system is busy financing the rich, totally ignoring the poor. Women are excellent entrepreneurs. If we create an appropriate financing system, all people, particularly women, will be able to demonstrate how skillful they can be as entrepreneurs. Our initiative to create a new banking system to give microcredit

to all poor people, particularly to women, has demonstrated it very clearly.

LB: The COVID pandemic has changed the world dramatically. What must we learn from this experience?

Professor Yunus: The pandemic has made it very clear how wrong our economic thinking is; how inadequate our institutions based on wrong thinking are; how fragile the economic existence of the poor is; how terribly lop-sided our wealth distribution is. Wealth is concentrated in the hands of a small number of lucky people. When the pandemic hit the world, millions of people who already had less were pushed under the poverty line, or brought closer to the line, while super rich people made trillions of dollars.

Our lesson is very clear — we must not go back to the old economic system when the pandemic is over. We must create a new system which will stop us from continuing our journey on the present suicidal path. We must build a new road to go to a new destination.

LB: In the two decades since becoming the WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa has made over 200 visits to more than 100 countries, seeing the situation for himself and conveying what he has seen and heard to their leaders. As soon as travel restrictions ease, he intends to resume his overseas missions. What advice do you have for him?

Professor Yunus: I congratulate Mr. Sasakawa for his commitment and dedication to the cause of eliminating leprosy from the world. His global campaign has drawn attention to the disease of leprosy all around the world. I very much hope that he'll promote a solution to leprosy within a clearly defined new healthcare system. This new system must be a social business healthcare system. This new system should be an alternative to the profit-maximizing healthcare system. I also hope that he'll promote the creation of social business pharmaceutical companies. I encourage him to lend his voice to change the system rather than looking for solutions within the system.

SPOTLIGHT

Entrepreneurial success in Bangladesh

Maksuda Khatun's life story exemplifies what can happen when an individual is given just enough financial or material support to start a business. At the age of 18, Maksuda noticed a white patch on her hand. With help from Lepra, a UK-based charity, she received treatment promptly, but her husband feared the disease and divorced her. She was able to move back to her parents' house with her young daughter, but she still had to figure out how to support herself.

A sewing machine and some training, provided by Lepra, allowed Maksuda to take her first step as a businesswoman. She worked as a tailor until she made enough money to start a poultry farm. Now her farm has over 1,000 broiler chickens and with the income she was able to support her daughter through completion of a physiotherapy degree. The chickens also help her family to meet their nutritional needs.

The COVID-19 pandemic has affected all aspects of her business, and she estimates that she has lost more than 400,000 taka (over US\$4,500) because of transportation shutdowns and other disruptions. Neighbors, some of whom had enthusiastically opened their own poultry farms after learning from Maksuda, are also seeing their businesses falter. Three farms have closed. With the entrepreneurial know-how that she has gained, Maksuda will do her best to continue being a leader in her community.



Dr. David Pahan, Country Director of Lepra Bangladesh, talking with Maksuda about her poultry farm.



Maksuda, a woman who has experienced leprosy, with the chickens on her poultry farm.

“Don’t forget leprosy” campaign update

World Leprosy Day has been observed annually on the last Sunday of January since 1954. The purpose of this day is to increase public awareness of leprosy (Hansen's disease). This year, the date will be Jan. 30, and with this in mind, the Sasakawa Leprosy (Hansen’s Disease) Initiative has made January into a month for raising the profile and reach of its 10-month “Don’t forget leprosy” campaign.

Message posted on WHO website

A message from Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, has been posted to the World Health Organization’s website. The message emphasizes the importance of early detection and treatment, even amid the COVID-19 pandemic, and the need to confront stigma and discrimination.



<https://www.who.int/news/item/10-01-2022-message-for-world-leprosy-day-2022>

Letters to health ministers

The Goodwill Ambassador wrote to health ministers and WHO representatives in 56 countries where leprosy is endemic to ask for their endorsement of the “Don’t forget leprosy” campaign. The many positive responses are encouraging. Country representatives can show their support publicly by posting on social media with the hashtags #DontForgetLeprosy and #DontForgetHansensDisease.



Twitter post by Dr. Annick Mondjo (@DrMondjo), Director of the Infectious Diseases Control Program at Gabon’s Ministry of Health, with the hashtag #dontforgetleprosy.

Grants for awareness-raising and surveys

In October 2021, the Sasakawa Health Foundation announced a “Don’t forget leprosy” grant program for two types of projects: 1) awareness-raising activities and 2) surveys of the situations of persons affected by leprosy and their families. Grants were awarded in December, and the project period started in January. More than 40 organizations — including NGOs, organizations of persons affected by leprosy, universities, research institutes, and medical associations — based in 16 countries received funding.

Of the 40 organizations that have received grants, 13 are in India, where around 60% of the world’s new cases of leprosy are diagnosed each year. Some of the awareness-raising activities being supported target school children and university students in the hope that discrimination can be eradicated if young people start their lives with accurate information about the disease.

In Brazil, the country with the second-highest number of annual new cases, grants are supporting the awareness-raising work of more than 2,000 persons affected by leprosy and volunteers from Morhan (Movement for the Reintegration of Persons Affected by Hansen’s Disease). Activities include a focus on healthcare professionals and involve training local public health nurses, strengthening the functions of leprosy referral centers, and case-finding.



Twitter post by St. Joseph’s Leprosy Hospital (@SJLH_FMMC), located in Mangalore, India, showing their awareness-raising activity supported by a “Don’t forget leprosy” campaign grant.



Facebook post about a meeting with Laura Carneiro, Rio de Janeiro’s Municipal Secretary of Social Assistance, where she agreed that the Secretariat of Social Assistance would join the “Don’t forget leprosy” campaign.

A month of activity for Global Appeal 2022

Initiated by the WHO Goodwill Ambassador for Leprosy Elimination in 2006, the annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy takes place annually in January in conjunction with World Leprosy Day. Each year, the Goodwill Ambassador reaches out to individuals and organizations from different fields to endorse a written statement and attend related events. This year, he invited philanthropic foundations to join him in calling for an end to marginalization of persons who have experienced leprosy and the realization of a just and equitable society that respects the human dignity and fundamental freedoms of all its members. Because of the COVID-19 pandemic, for the second year in a row all Global Appeal-related activities will take place online.

Jan. 9: Photo contest

In October, Sasakawa Leprosy (Hansen's Disease) Initiative announced a social media photo contest with the theme "Don't forget leprosy." Participants were advised to post photos with the hashtags #DontForgetLeprosy, #DontForgetHansensDisease, and #GA2022 depicting the daily lives of persons affected by leprosy and any activities undertaken during the pandemic to support their communities. Jan. 9 was the deadline for participation, and selected photos can be viewed on the Global Appeal website.



Results of the photo contest posted at <https://bit.ly/3KwCLJs>



Jan. 20 and 25: Webinars

"Role of Health Professionals at the Grassroots Level"

This webinar, held on Jan. 20, focused on the efforts of healthcare professionals who work at the grassroots level to detect leprosy cases and prevent disability amid the COVID-19 pandemic. Some success stories were introduced as potential best practice models that participants could adapt for their local circumstances. A recording of this webinar is available on the Global Appeal website.

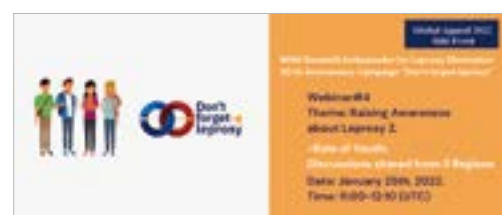


Recording of the webinar available at <https://bit.ly/3loDmeg>



"Role of Youth: Discussions Shared from 3 Regions"

Later this year, for the first time, the Initiative will host a Global Youth Forum to stimulate discussions between young people working to solve leprosy issues and leaders of people's organizations. In preparation, three regional meetings were held in December 2021 and January 2022 (see page 7). At the webinar on Jan. 25, young participants shared the results of their regional meetings and discussed their role with the WHO Goodwill Ambassador. A recording of this webinar is available on the Global Appeal website.



Recording of the webinar available at <https://bit.ly/3loDmeg>



Jan. 28: Website

A dedicated website for the Global Appeal launched on Jan. 28. In addition to the content described above, the website includes video messages from invited contributors and edited interviews of the Goodwill Ambassador and Mr. Jamshyd Godrej, President of CII Foundation, on the topic of what philanthropic foundations must do to demonstrate that they have not forgotten leprosy.



Global Appeal website
<https://gasasakawa.org>



REPORT



Five members of Morhan's Women's Policy Department (DPW-Morhan) contributed to this report:

Paula Brandão, woman affected by Hansen's disease and coordinator of the Morhan Research Center; **Patricia Soares**, woman affected by Hansen's disease and DPW-Morhan coordinator; **Francilene Mesquita**, woman affected by Hansen's disease and DPW-Morhan coordinator; **Suerli Oscar**, daughter of a person affected by Hansen's disease and DPW-Morhan coordinator; and **Nanda Duarte**, communication advisor for Morhan.

<http://www.morhan.org.br>

We need to hear what girls and women affected by Hansen's disease have to say

Women and girls have been part of the Movement for the Reintegration of Persons Affected by Hansen's Disease (Morhan) since its foundation in 1981 in Brazil. The experience of discrimination experienced by women affected by Hansen's disease and the social vulnerabilities associated with gender issues led to the formation of the Women's Policy Department (DPW-Morhan) in 2018.



DPW-Morhan encourages local movement centers to connect women to one another so that they can support one another in person and coordinate to take action in the community. The first "Women of Morhan" in-person meeting was held in Piauí (northeastern Brazil) in August 2019. The creation of a WhatsApp group two months prior to the meeting facilitated communication. In the words of one of the organizers, Francilene Mesquita, "Our union went from the virtual world to the real world."

In 2021, in the face of the political-health crisis produced by the COVID-19 pandemic and the violation of the right to health, the women of DPW-Morhan together with Alice Cruz, UN Special Rapporteur, decided to listen to and amplify the voices of women and girls affected by Hansen's disease so that they would reach people around the world. We organized the first international meeting of "Hansen's disease and the right to health: what girls and women have to say." The meeting was divided into five sessions lasting three hours: two sessions for women from Brazil only and three regional sessions for women from the Americas, Africa and Asia. In total, 107 women from 15 countries participated. Sasakawa Health Foundation provided support for professional translation into English, French, and Spanish. Volunteers provided additional translation into Hindi, Bengali, Nepali, and Indonesian.

The women were encouraged to tell their stories by answering the following questions: a) What are the problems faced



Social media advertisement for the first international meeting of "Hansen's disease and the right to health: what girls and women have to say," organized by Morhan's Women's Policy Department (DPW-Morhan).

by women and girls affected by Hansen's disease as an individual, in the family, and in the community? b) What are the possible causes of these problems? c) What do women and girls affected by Hansen's disease want? The women talked about problems related to illness, such as difficulty in accessing health services and treatments, late diagnosis, and lack of adequate information about issues specific to being female. And they spoke especially about the consequences of the experience of being an affected woman, such as discrimination in the family and community, damage to mental health, overload of domestic work, difficulties with economic self-support such as unemployment or underemployment, lack of government-sponsored assistance programs, not being able to attend school, domestic and sexual violence, and separation from children and/or spouse.

The meeting generated a report that was shared with the special rapporteur and an article to be published soon, which details the problems and recommendations suggested during the meetings. Our next steps are to strengthen the network of women affected by Hansen's disease in Brazil and to increase exchange experiences with women from other countries through people's organizations. At the heart of our action is the certainty that it is necessary to listen to girls and women affected by Hansen's disease so that public policies around the world address the burdens particularly placed on them and recognize them as subjects of rights.

Three regional meetings held in preparation for first Global Youth Forum

The Nippon Foundation and Sasakawa Health Foundation, now working together as the Sasakawa Leprosy (Hansen's Disease) Initiative, have been supporting the empowerment of persons who have experienced leprosy for nearly 30 years. During this time period, people's organizations have grown in number and scale. Along with growth comes the challenge of sustainability. In line with its goal of strengthening the leprosy community through a multilayer approach, the Initiative looks for ways to build the leadership capacity of young people as a way to help people's organizations achieve their long-term goals. The 10-month "Don't forget leprosy (Hansen's disease)" campaign provides a framework for involving youth in discussions of what needs to be done even amid the COVID-19 pandemic. A new event called the Global Youth Forum was added to the agenda with the capacity-building goal in mind.

To be held online later this year, the Global Youth Forum will identify young people who work on leprosy-related problems, encourage them, and provide them with an opportunity for interaction with their peers in other countries and representatives from more experienced generations. It is hoped that the connections that participants make during this event will generate new possibilities for international and intergenerational collaboration.

In preparation for the Forum, the Initiative worked with people's organizations to organize three regional meetings for Latin America and the Caribbean, Asia, and Africa. These were held online in December 2021 and January 2022. The results of the regional meetings were shared at a follow-up webinar titled "Role of Youth."

Latin America and the Caribbean

The "Latin American and Caribbean Virtual Meeting of Young People Affected by Leprosy, Family Members, and Supporters" was organized by the Intergenerational Department of Morhan (Brazil) and held on Dec. 11, 2021. The online event was attended by 54 young persons affected by Hansen's disease and their family members from Brazil, Colombia, Nicaragua, and Peru. Prior to the event, participants were encouraged to answer five questions. At the event, two young leaders from Morhan, Marcos Costa and Tatielle Naiara, used these questions to facilitate discussion. The meeting concluded with some specific action-oriented suggestions.

Asia

The "Asia Youth Forum" was co-created by three organizations — HANDA (China), PerMaTa South Sulawesi (Indonesia), and YDTI (Indonesia) — and held on Dec. 16, 2021. More than 100 participants from Bangladesh, China, India, Indonesia, and Nepal joined the event. The Asia forum consisted of three thematic sessions: how to reduce stigma, how to promote engagement of youth; and how to improve access to health services and rehabilitation. Afterward, HANDA observed that there seemed to be potential for creating a regional coalition for youth activities.



HANDA Yunnan (China) leadership members saying slogan out loud: "For a better life, let's fight against leprosy discrimination!"

Africa

The "Africa Youth Forum" was organized by ENAPAL (Ethiopia) and held on Jan. 11, 2022. Participants joined from Niger, Kenya, Nigeria, Tanzania, Senegal, Sierra Leone, Mozambique, and Ethiopia. Joshua Mamane from Niger pointed out in his presentation that "youth" is a symbol of mobility, dynamism and innovation, and so involving young people could generate new solutions.

"Role of Youth" webinar

Conclusions from the three regional meetings and suggestions for the Global Youth Forum were shared in a webinar held on Jan. 25 in affiliation with the 2022 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy. WHO Goodwill Ambassador Yohei Sasakawa joined the webinar to hear firsthand from the young participants and contribute his thoughts on their role.

WISHLIST

With World Leprosy Day approaching, the *Leprosy Bulletin* asked two people involved in “Don’t forget leprosy” activities for three wishes related to how they would like the world to change for persons affected by leprosy. Maksuda Khatun, who successfully makes a living raising chickens after being diagnosed with leprosy at age 18 (see page 3), shared her wishes from Bangladesh. Dr. Michael Chen, a leader of HANDA and an organizer of the Asia Youth Forum (see page 7), offered his wishes from China.



Maksuda Khatun
Treasurer,
Sirajganj District Leprosy
and Disability Federation
Sirajganj, Bangladesh

- 1** A stigma-free society that is committed to combating discrimination and supporting the mental health and well-being of all people, including persons affected by leprosy.
- 2** A society where persons affected by leprosy can participate in all social and cultural activities without fear of discrimination and women have equal opportunity in every sector.
- 3** Easy access to government facilities that support improved living conditions for persons affected by leprosy.

- 1** A strong network of persons affected by leprosy, their families, community members, and people’s organizations who work in solidarity to create a society where people are assured a dignified life in an equitable and discrimination-free environment and where elderly persons affected by leprosy are given sufficient social attention and quality services in their later years of life.
- 2** Widespread awareness that the history of leprosy and the life experiences of persons affected by leprosy can be a precious textbook for policy makers and the public to learn from when coping with unknown contagious diseases.
- 3** As called for in the Charter on Inclusion of Persons with Disabilities in Humanitarian Action, ensure that persons affected by leprosy have access to information, services, and treatment. All people should have protection and the means to stay healthy amid the COVID-19 pandemic.



Dr. Michael Chen
Secretary General,
HANDA Rehabilitation &
Welfare Association
China

