

LEPROSY BULLETIN

NO. 118 DECEMBER 2023



State leaders make a difference

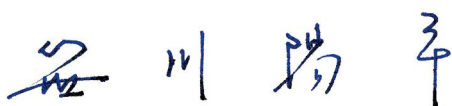
Message from the ambassador

On Nov. 12, Bangladesh held the “2nd National Leprosy Conference 2023” in Dhaka. The event follows up on the first National Leprosy Conference, held in December 2019, where Prime Minister Sheikh Hasina urged all present “to build a leprosy free Bangladesh by 2030.” Encouraged by her strong message, I wanted to help, but just as discussions were starting to get underway, the COVID-19 pandemic forced all plans to be put on hold.

When I returned to Bangladesh for the first time in four years this past September, I had the opportunity to meet again with the Prime Minister. Recalling her declaration and the energy that it had set in motion, I asked her to hold another conference so that the momentum would not be lost. I emphasized that even just 30 minutes of her time would make a difference and that a directly delivered message would bring light to persons affected by leprosy who suffer from unjust stigma and discrimination. Fortunately, she agreed.

At the 2nd National Leprosy Conference, the Prime Minister called for increasing Bangladesh’s budget for leprosy elimination in order to reach zero by 2030. She also spoke passionately about the need to welcome persons affected by leprosy into the mainstream of society.

Some may see the “zero leprosy by 2030” goal as overly ambitious. I believe that debate will not reveal the goal’s value; its value will emerge as stakeholders rally around it and work to make it a reality. Personally, I will do all I can to help Bangladesh achieve its goal, and I hope that the actions taken in the direction of zero leprosy will generate models for other countries as well.



Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Artur Custódio Moreira de Sousa
MORHAN (Brazil)

Dr. Beatriz Miranda Galarza
United Nations Special Rapporteur

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

Bangladesh's Second National Leprosy Conference

Bangladesh's Ministry of Health and Family Welfare, with support from the Sasakawa Leprosy (Hansen's Disease) Initiative, held the 2nd National Leprosy Conference in Dhaka on Nov. 12, 2023. The conference brought together medical and public health administration experts, NGO leaders, and representatives of organizations of persons affected by leprosy to reinvigorate efforts toward achieving the goal set by Prime Minister Sheikh Hasina four years ago at the first conference: zero leprosy by 2030.



“Zero Leprosy by 2030”

“Leprosy is not a curse, but a disease infected through the transmission of bacteria. I urge all health department officials, field level staffs and all concerned to work altogether, and strengthen and accelerate the national leprosy activities to build a leprosy free Bangladesh by 2030.”

**The Honorable Prime Minister Sheikh Hasina
December 11, 2019
National Leprosy Conference- 2019 on ‘Zero Leprosy Initiative-2030’**

The *National Strategic Plan for Leprosy in Bangladesh 2023–2030* (p. 17) reminds stakeholders of the “Zero Leprosy by 2030” declaration made by Prime Minister Sheikh Hasina at the first National Leprosy Conference in 2019.

Approximately 500 people attended the morning’s Inaugural Session, where speeches were delivered by Prime Minister Sheikh Hasina; Minister of Health and Family Welfare Zahid Maleque; Secretary of the Ministry of Health and Family Welfare’s Health Services Division Md. Jahangir Alam; and WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa. Technical sessions included contributions from invited panelists Dr. Vivek Lal, Team Leader of WHO’s Global Leprosy Program; Dr. Joydeeba Darlong, Head of Knowledge Management at TLM Trust India; and Dr. Takahiro Nanri, Executive Director of Sasakawa Health Foundation.

Goodwill Ambassador Sasakawa said that Prime Minister Sheikh Hasina's call for “zero leprosy by 2030” at the first

conference in 2019 marked the first time that such a precise goal had been set by a national leader. He thanked the Prime Minister for her bold decision, stating that it has given hope to Bangladesh's persons affected by leprosy and their family members who still suffer from stigma and discrimination. He pointed out that detection, diagnosis, and treatment efforts stagnated globally during the COVID-19 pandemic, resulting in a misleading statistical decline in the number of new cases. After denouncing the discrimination “rooted so deeply and silently in society,” he asked all participants to work together to realize a world free of leprosy.

Prime Minister Sheikh Hasina reminded participants that discrimination against persons affected by leprosy has no place in the government’s “Smart Bangladesh” vision for a prosperous, equitable, and sustainable future. She declared that persons affected by leprosy must be provided employment opportunities and called on domestic pharmaceutical companies to manufacture leprosy-specific medications. She mentioned increasing funds to accelerate the National Leprosy Program as one of the initiatives necessary for achieving zero leprosy by 2030.

The National Leprosy Strategy for 2023-2030, shared in a presentation and a printed booklet, emphasizes four pillars:

1. Strong National Leprosy Program (NLP)
2. Integrated active case detection
3. Integrated case management
4. Community inclusive implementation

The country’s National Leprosy Program is planning to organize workshops with health care providers in 64 districts, to be followed by awareness raising and patient detection activities at the sub-district level. These efforts are part of establishing a system that encourages everyone – not just the central government – to take action toward zero leprosy.



Participants at Bangladesh's 2nd National Leprosy Conference held in Dhaka on Nov. 12, 2023, raise placards to signal their commitment to reaching zero leprosy by 2030.



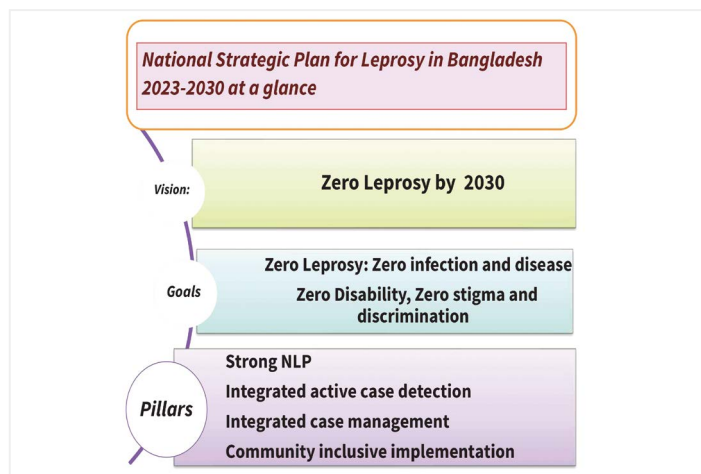
Prime Minister Sheikh Hasina requests that all citizens bring persons affected by leprosy into the mainstream of society with love, compassion, and affection.



WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa declares that he will spare no effort to help Bangladesh reach its goal of zero leprosy.



The main speakers at the Inaugural Session, including Prime Minister Sheikh Hasina (center left), hold up copies of the *National Strategic Plan for Leprosy in Bangladesh 2023-2030*.



Excerpted image from page 18 of the *National Strategic Plan* booklet shows the four pillars that will receive priority as Bangladesh works toward zero leprosy by 2030.



Minister of Health and Family Welfare Zahid Maleque presents a bouquet of flowers to honored guest Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination.



A poster with a photograph of Prime Minister Sheikh Hasina connects the “zero leprosy by 2030” goal to the government’s “Smart Bangladesh” vision for the nation.

REPORT



Artur Custódio Moreira de Sousa

Volunteer

Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN)

MORHAN is a non-profit organization and social movement in Brazil that raises awareness of Hansen's disease as a curable disease and advocates for public policies that uphold human rights and support effective treatment.

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

New “reparation law” in Brazil comes with official apology to children separated from their parents

On Nov. 24, 2023, President Luiz Inácio Lula da Silva marked a significant chapter in Brazil's history by promulgating Law 14736 and calling it a "historical reparation for the mistakes of the Brazilian state."

Sixteen years after Law 11520 of Sept. 18, 2007, secured a monthly, lifelong pension for persons affected by Hansen's disease who were forced to isolate in colony hospitals, this new “reparation law” adds eligibility for those who were made to isolate at home or in the Amazon jungle as well as children who were separated from their parents.

The reparation law is the result of over a decade of persistent effort. In 2009, two years after the promulgation of Law 11520, MORHAN initiated nationwide discussions about the issue of separated children, and in 2011, six bills on the topic were presented in the Chamber of Deputies. Four years later, in 2015, additional bills sought coverage for persons affected by Hansen's disease who were made to isolate at home or in the Amazon jungle because of overcrowding in colony hospitals.

During Dilma Rousseff's presidency (2011–2016), a team in the Ministry of Human Rights proposed and approved a substitute law. The Ministry of Health also approved, but the law stalled in the Ministry of Finance because there were no studies at the time estimating the financial impact of the law on the budget. With the coup that ousted President Rousseff, progress halted entirely.

Finally, in 2022, everything started coming together. A new comprehensive bill, Bill 3023, sought to amend Law 11520 to cover all persons affected by Hansen's disease forced into isolation or hospitalization by the state and the children who were separated from them. The bill managed to advance in both committees of the Chamber of Deputies and progress to the Federal Senate. After President Lula's administration came to power on Jan. 1, 2023, the bill passed through the Federal Senate rapidly, receiving urgent approval in just nine months.

President Lula, who was scheduled to be out of the country soon for an international conference, decided to sign the bill into law before the legal deadline. MORHAN mobilized

quickly, and in just four days, managed to bring approximately 550 separated children, ages 40 to 90, on bus trips ranging from 6 to 26 hours to Brasília to witness the ceremony. For anyone who could not be there, the signing ceremony was broadcast live by government channels and extensively covered by the press.

MORHAN celebrates the signing of Law 14736 as not only a legislative milestone but also as an instance of progress in transitional justice. By confronting its painful history, apologizing for it, and making reparations, the state demonstrates its commitment to truth, justice, and building a more inclusive future.

May this law be the first of many steps toward a more empathetic and equal society, and may this successful outcome encourage organizations of people affected by Hansen's disease to continue the fight for human rights. We will still face many battles, whether against the disease and its stigma or for the incorporation of new drugs and technologies. As progress is made, we must preserve isolation sites as sensitive heritage, witnesses of pain, and traumatic spaces that remind us of actions that should never be repeated in human history.



Brazil's President Luiz Inácio Lula da Silva (center) and Health Minister Nísia Trindade (center right) celebrate the signing of Law 14736 (“the reparation law”) with MORHAN representatives on Nov. 24, 2023. Photo © Ricardo Stuckert 2023.

LETTER



Dr. Beatriz Miranda Galarza
United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members

Based on a mandate established by the UN Human Rights Council in June 2017, the Special Rapporteur undertakes fact-finding country visits and informs Member States and the Human Rights Council about alleged violations of the rights of persons affected by leprosy and their family members.

New UN Special Rapporteur invites all to explore together ways to achieve social justice

On Nov. 1, 2023, I was appointed Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members. This rather long title comes with an enormous responsibility and with great possibilities for learning about our human condition. It is a pleasure to write this short piece realizing friends and colleagues, old and new, will receive it. My thanks go to the Sasakawa Leprosy (Hansen's Disease) Initiative for giving me this opportunity, and I would also like to acknowledge the work of Dr. Alice Cruz and thank her for all the doors she opened during her mandate.

My professional background is in the fields of sociology and anthropology. I have worked for 30 years in the domain of health and disability, and the last 13 of these years have been dedicated to the Hansen's disease arena. Currently, I am the coordinator of the Critical Disability Studies Programme at 17, Institute of Critical Studies in Mexico City. My family, like many of the families of persons affected by leprosy, faces daily challenges in advocating for the rights of my siblings with both intellectual and physical disabilities. This unique experience has profoundly shaped my perspective on life and the world.

In 2010, I was given the unique opportunity to work together with persons affected by leprosy in Indonesia. Later, this experience extended to Nepal, Myanmar, India and Timor Leste as well as Brazil, Colombia, Ecuador, and Mexico. Learning together with many organizations of persons affected by leprosy and persons with disabilities in participatory action research projects has transformed my view of what life means. This work and these experiences have resulted in a deep appreciation of the daily experiences of persons, families, and communities who must deal with the impact of leprosy at different levels and in different spheres. An essential lesson I have reflected on is how integral the development and strengthening of compassion is to the fight for the respect of our collective and individual rights. Compassion is understood here as the possibility to recognize our own suffering and the ability we have to transform it. This involves recognizing the suffering of others as well as

supporting and accompanying them during the process of their transformation. Allowing ourselves to be touched by our own suffering and that of others demands transformative action that will affect our internal and external world.

My work in the leprosy field has taught me that fighting for recognition of our rights cannot be separated from recognition of our own dignity. Thus, I invite each of you to join me on this journey as we explore ways to achieve social justice by following the path of kindness and compassion.



In 2018, Dr. Beatriz Miranda Galarza spent time with members of Partnership for New Life (PNL) in Butwal, Nepal. PNL is a nonprofit organization that has been offering treatment and disability care services to persons affected by leprosy since 2005.



In 2011, Dr. Beatriz Miranda Galarza worked with staff involved in the Stigma Assessment and Reduction of Impact (SARI) project in Cirebon, Indonesia, to learn about becoming aware of the value of personal knowledge.

Bergen holds world's first international film festival on Hansen's disease

Contributed by Mao Hasebe, Program Officer, Sasakawa Health Foundation

The Sasakawa Leprosy (Hansen's Disease) Initiative, in collaboration with the University of Bergen and the Leprosy Museum, worked with the Bergen International Film Festival (BIFF) to offer the Armauer Hansen International Film Festival Oct. 24–26, 2023. Named after Dr. Gerhard Armauer Hansen, who discovered the leprosy bacillus while working at Bergen's St. Jørgen's Hospital 150 years ago, in 1873, the festival is the world's first international film festival on Hansen's disease.

According to the BIFF web page that promoted the event, despite the fact that the leprosy bacillus was discovered in Bergen, many of the Norwegian city's residents are unfamiliar with the disease and its stigma. The festival was intended to spread awareness by sharing documentaries and fiction films that show how the disease has affected people in various historical and social contexts.

To choose the films, the Initiative asked organizations by and for persons affected by leprosy and NGOs for recommendations. From these recommendations, the Initiative created a short list, which was provided to BIFF. Uday Thakar, an advisor for APAL (India), and Artur Custódio, a volunteer for MORHAN (Brazil), provided guidance during several online meetings. The final selections included two short films and four full-length films.

A pre-festival event on Oct. 23 offered a special screening inside the historic St. Jørgen Church at the Leprosy Museum. Sitting in the pews where residents of St. Jørgen Hospital once sat and prayed, the audience watched the two short films – *Children of Leprosy* and *The Village* – which show examples of the present-day consequences of historical policies of compulsory isolation. After the screening, the audience engaged in discussions and a tour of the Leprosy Museum's grounds.

During the three days of the festival, 315 people attended screenings in two Bergen cinemas of the four full-length films: *The Last Mile*, *Sweet Bean*, *Yomeddine*, and *The Motorcycle Diaries*.

Through BIFF's School Program, the Armauer Hansen International Film Festival was able to share *The Last Mile*, a documentary about the work of the WHO Goodwill Ambassador for Leprosy Elimination, with 152 students from five high schools. In-class study materials helped the students prepare before watching the film, and afterward

they were given the opportunity to ask questions directly to the Goodwill Ambassador or Dr. Takahiro Nanri, Executive Director of the Sasakawa Health Foundation.

The Sasakawa Leprosy (Hansen's Disease) Initiative would like to give heartfelt thanks to Alexander Petersen, Project Manager; Tor Fosse, Festival Director; Magnus Holtermann, Head of Administration; Håkon Tveit, School Program Lead; and all BIFF staff involved in realizing this special film festival. The Initiative is also grateful to Uday Thakar and Artur Custódio for their valued guidance and support as well as all partners who have helped with gathering information about films and documentaries on Hansen's disease from around the world.



Grete Eilertsen, a museum educator for the Bergen City Museum foundation, makes opening remarks before the screening of two documentary films at St. Jørgen Church on Oct. 23, 2023.



Yohei Sasakawa (front row, fourth from left), WHO Goodwill Ambassador for Leprosy Elimination, and Alexander Petersen (foreground right), a project manager for the Bergen International Film Festival, together with high school students who watched the documentary *The Last Mile* as part of the School Program.

Goodwill Ambassador visits Bergen, Norway, and Dhaka, Bangladesh

Armauer Hansen International Film Festival

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa made a whirlwind trip to Bergen, Norway, to attend the opening of the Armauer Hansen International Film Festival on Oct. 24, 2023. The festival was co-sponsored by the Bergen International Film Festival (BIFF) and the Sasakawa Leprosy (Hansen's Disease) Initiative to commemorate the 150th anniversary of the discovery of leprosy bacillus by Dr. Hansen.

In the afternoon before the official opening, the Goodwill Ambassador attended two screenings of *The Last Mile: On the Road to Eliminate Leprosy*, a documentary about his efforts directed by Naohiro Asano (2017), so that he could talk with high school students who were attending as part of BIFF's School Program. Speaking with 48 students after the first screening and 56 students after the second, he answered questions about how leprosy is transmitted and the progression of the disease. Some of the students expressed surprise about issues that they learned about for the first time. He told the teenagers that he hopes that Norway, as a global leader in the field of human rights, will actively contribute to the elimination of discrimination against persons affected by leprosy.



Goodwill Ambassador Sasakawa answers questions from high school students along with Alexander Petersen, a project manager for the Bergen International Film Festival, following a screening of the documentary *The Last Mile* on Oct. 24, 2023.



A Bergen high school student takes a selfie with the Goodwill Ambassador after a discussion about *The Last Mile: On the Road to Eliminate Leprosy*.

Second National Leprosy Conference

The Goodwill Ambassador visited Dhaka, Bangladesh, to attend the 2nd National Leprosy Conference. On Nov. 11, 2023, the day before the conference, he appeared on a DBC News one-hour talk show with Dr. Ahamedul Kabir, Additional Secretary of Bangladesh's Ministry of Health and Family Welfare, and Mr. Kamal Uddin, Chairman of the ALO Society, an organization of persons affected by leprosy.



From left, Dr. Ahamedul Kabir, Additional Secretary of Bangladesh's Ministry of Health and Family Welfare; Mr. Md. Kamal Uddin, Chairman of the ALO Society; WHO Goodwill Ambassador Yohei Sasakawa; and Ms. Fahmida Shompa, the news anchor who hosted the one-hour talk show on DBC News (<https://youtu.be/UNtF0NuqGEo>).

At the 2nd National Conference on Nov. 12, Prime Minister Sheikh Hasina gently joked to Goodwill Ambassador Sasakawa, "I heard that you are going to attend the conference, and so I decided to attend as well." Of course, her presence was actually the result of months of work by everyone involved in organizing the conference. The event helped to strengthen the relationships needed to eliminate leprosy from Bangladesh by 2030. The Goodwill Ambassador conveyed his desire to visit endemic areas to promote awareness.



WHO Goodwill Ambassador Yohei Sasakawa shares a light moment with (from left) Md. Jahangir Alam, Director General of the Health Services Department; Zahid Maleque, Minister of Health and Family Welfare; and Prime Minister Sheikh Hasina at Bangladesh's 2nd National Leprosy Conference in Dhaka on Nov. 12, 2023.

ANNOUNCEMENT

New book published about the work of the Goodwill Ambassador

Leprosy has been a source of suffering for so long that it is perhaps difficult to imagine a world without it. But it is an attainable goal, and one that is coming closer, thanks to the dedication of people such as Mr. Yohei Sasakawa.

—Dr. Tedros Adhanom Ghebreyesus, Foreword,
A Global Impact

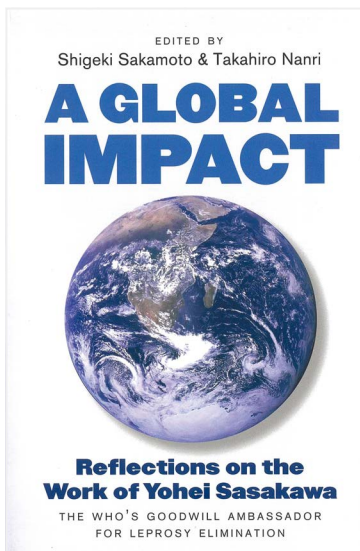
In 2001, Yohei Sasakawa was appointed WHO Special Ambassador to the Global Alliance for Elimination of Leprosy (GAEL). Following GAEL's dissolution, the appointment was retitled WHO Goodwill Ambassador for Leprosy Elimination. Dr. Shigeki Sakamoto, a former member of the Advisory Committee of the UN Human Rights Council, and Dr. Takahiro Nanri, Executive Director of the Sasakawa Health Foundation, have used the occasion of Sasakawa's 20th year as Goodwill Ambassador to pull together an edited volume that reflects on his work.

Published in English by London-based C. Hurst & Co. (Publishers) Ltd., *A Global Impact: Reflections on*

the Work of Yohei Sasakawa, the WHO's Goodwill Ambassador for Leprosy Elimination, consists of a foreword by Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, and seven chapters by six contributors.

Each chapter aims to identify Sasakawa's methods and contributions in order to extract lessons and models with relevance for fighting other infectious diseases and actualizing the "leave no one behind" principle of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs). Themes addressed include public health, human rights, empowerment of the people most affected (primary stakeholders), public awareness, and the significance of a leader's personal qualities and commitments.

The book will be of interest to any individual or organization tackling a complex, global issue that requires efforts at all levels of society to solve.



Published November 2023
C. Hurst & Co. (Publishers) Ltd., London
248 pages, 8 color illustrations
ISBN: 9781805261292

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A Global Impact: Reflections on the Work of Yohei Sasakawa

<https://bit.ly/4anRjyu>



**SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE**

WHO Goodwill Ambassador's Leprosy Bulletin No.118

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The *Leprosy Bulletin's* content is posted online at
[https://sasakawaleprosyinitiative.org/latest-updates/
initiative-news/](https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/)



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