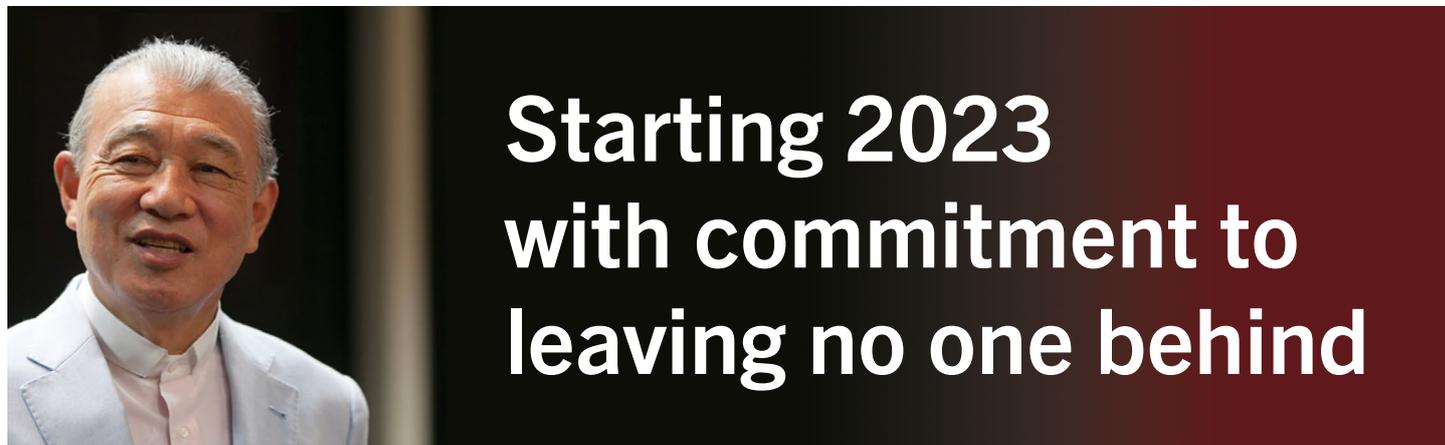


LEPROSY BULLETIN

NO. 113 FEBRUARY 2023



Message from the ambassador

On Jan. 23-24, 2023, the International Symposium at the Vatican on Hansen's Disease was held at the Augustinian Patristic Institute, in cooperation with the Dicastery for Promoting Integral Human Development, on the theme "Leave No One Behind." The 18th Global Appeal, held every year in proximity to World Leprosy Day since 2006, was launched during the Symposium and endorsed by organizers and participants.

About 130 people from more than 20 countries participated in the Symposium, including government officials, international organizations, leprosy-related groups, non-governmental organizations, researchers, and media representatives. Volker Türk, United Nations High Commissioner for Human Rights, and Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, sent video greetings. Pope Francis provided a written message.

Following the Symposium, on Jan. 26, I had the honor of a private audience with the Pope. To eliminate stigma and discrimination associated with leprosy, cooperation of the Catholic Church, which has over 1.3 billion members worldwide, is essential. I hope that the connections that were made this January will catalyze positive change.

My thoughts align with these words from the Pope's message: "We must not ignore this disease, which unfortunately still afflicts many people, especially in the most disadvantaged social contexts. . . . I hope that this conference may contribute to bringing together voices from all over the world to discuss the measures that can be adopted to further promote respect for human dignity." Under the banner of "Don't Forget Leprosy / Don't Forget Hansen's Disease," may we all work together to help as many people as possible!

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Vivek Lal

Team Leader, Global Leprosy Programme (WHO)

Magnus Vollset

Associate Professor, University of Bergen

Pragnya Ayyagari

Miss Supranational India 2023

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

VIEWPOINT



Dr. Vivek Lal
Team Leader, Global Leprosy Programme, World Health Organization (WHO)

Dr. Vivek Lal has an MD Community Medicine and over 16 years of public health experience involving advocacy, planning, implementation, and research. In December 2022, he assumed the role of Team Leader of WHO's Global Leprosy Programme. The main objective of the program is to ensure that the disease burden continues to decline in all countries.

New Team Leader of WHO's Global Leprosy Programme shares vision

Towards a world with zero leprosy

WHO is committed to supporting leprosy-affected countries to achieve zero leprosy disease, zero leprosy disability, and zero leprosy stigma and discrimination by 2030 — the vision of the WHO Global Leprosy Strategy 2021–2030.¹

In 2021, a total of 140,594 new cases of leprosy were detected, corresponding to a new case detection rate of 17.8 per million population globally. Of these new cases, 9,054 (6.4%) were children and 8,042 (5.7%) were detected with visible deformities or grade 2 disabilities.

Globally, leprosy shows a clustered distribution, with 95% of new cases coming from 23 Global Priority countries. Brazil (13%), India (54%), and Indonesia (9%) together account for 75% of new cases.

The COVID-19 pandemic has caused significant service disruptions, including for community-based interventions — such as active case-finding — and health facility-based services. Between 2019 and 2020, new case detection declined by 37%, from 202,185 to 127,396, respectively.

In 2021, there was a marginal improvement, as evidenced by the 10% increase in new case detection. However, we must now ensure that leprosy services are fully restored, and that they rapidly reduce the existing backlog of cases to avoid deformities and/or further worsening of disabilities.

In addition to COVID-19-related challenges, stigma and discrimination continue to impede prompt diagnosis and treatment as well as inclusion and participation of persons affected by leprosy. In 2021, at least 115 discriminatory laws were reported to be in place in seven countries, and 124 instances of discrimination were reported.

In recent years, single-dose rifampicin as preventive chemotherapy has proven effective in reducing the risk of leprosy in contacts of leprosy patients. This has enabled us to aim to interrupt transmission and achieve zero new autochthonous cases, as per the Global Leprosy

Strategy, which is one of several disease-specific strategies underpinning the WHO road map for neglected tropical diseases (NTDs) 2021–2030².

The Strategy consists of four pillars:

- 1) implementing integrated, country-owned zero leprosy roadmaps;
- 2) scaling up leprosy prevention, alongside integrated active case detection;
- 3) managing leprosy and its complications and preventing new disability; and
- 4) combating stigma and ensuring human rights are respected.

Next steps

Affected countries must adopt, adapt, and implement the Strategy in full, and with maximum accountability. At the same time, together we must increase research and development on point-of-care diagnostic tests, more effective drugs or drug combinations, and shorter regimens, and also develop and implement inclusive approaches for community-based rehabilitation and stigma reduction. For this, several tools are already available, including guidelines for the diagnosis, treatment and prevention of leprosy (WHO, 2018); technical guidance on contact tracing and post-exposure prophylaxis (WHO, 2020); a strategic framework for integrated control and management of skin-related neglected tropical diseases (WHO, 2022); and self-learning virtual modules available on the Open WHO platform³. Actions are needed to increase awareness of their availability and promote usage in the context of a defined strategic approach.

In the months and years ahead, WHO will continue to support all leprosy-affected countries to drive rapid, equitable, and sustained progress towards our targets and goals, achieving zero leprosy disease, zero leprosy disability, and zero leprosy stigma and discrimination by 2030, leaving no one behind.

¹ *Towards zero leprosy. Global leprosy (Hansen's Disease) strategy 2021–2030* (<https://www.who.int/publications/i/item/9789290228509>).

² *Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical*

diseases 2021–2030 (<https://www.who.int/publications/i/item/9789240010352>).

³ For example, *Leprosy: training of health workers on skin-NTDs* (<https://openwho.org/courses/NTDs-leprosy>).

ANNOUNCEMENT

**Magnus Vollset**

Associate Professor
Department of Global Public Health and Primary Care, University of Bergen
<https://www.uib.no/en/globpub>

Head of 2023 Hansen Anniversary program committee
<https://hansen2023.org/>

Anniversary events being organized in Bergen, Norway, 150 years after Hansen's discovery

On the evening of Feb. 28, 1873, Gerhard Armauer Hansen observed, for the very first time, small rod-shaped organisms in tissue samples from one of his patients. Though the rods were microscopic, the implications were enormous. Hansen had discovered the pathogen causing leprosy: *M. leprae*.

The discovery reduced the power of superstitions by giving the feared disease a rational explanation. It had enormous consequences for preventive medicine and health legislation in Norway and globally.

Despite the progress that has been made in the 150 years since the discovery, leprosy still has yet to be eradicated. The University of Bergen and the Sasakawa Leprosy (Hansen's Disease) Initiative are working together to commemorate the watershed moment of Hansen's discovery by hosting events that prompt reflection on the past, consideration of the present, and build momentum for a future where the disease remains only in history books and museums.

Event and webcast in February

On the anniversary of the discovery, Feb. 28, visitors to Bergen can attend an event in the university's ceremonial hall. On the same day, we will host a webcast for anyone who cannot attend in person.

In preparation, we have been filming in several locations, including the Bergen Leprosy Museum, the Armauer Hansen Commemorative Room, and the Bergen State Archives. The 75-minute webcast will feature interviews and conversations with experts from various fields, testimonies, greetings, and more — including a performance of a lamentation written by a patient around 1830.

Both in-person participants and webcast viewers will learn more about Hansen, his discovery, and its consequences as well as about leprosy history preservation more widely. Thoughts on the present situation and strategies for the near future will also be shared.

The anniversary event will also be a time for critical reflection. A presentation that discusses how Hansen's legacy is

preserved and communicated in Bergen will acknowledge the discovery's mixed effects, including justification for cruel segregation and human experimentation.

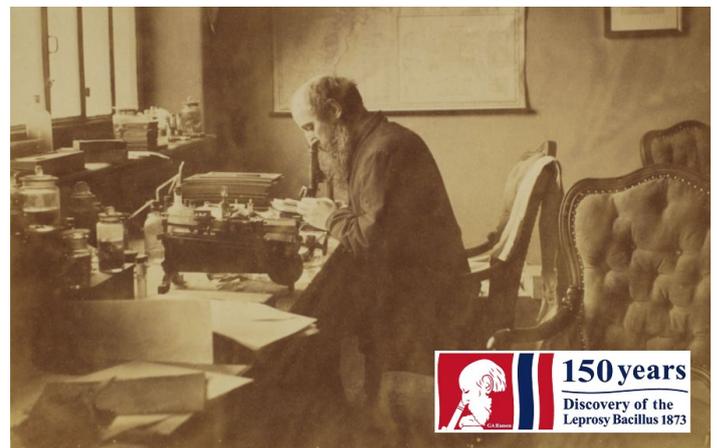
Conference in June

The anniversary's largest event will be a conference held June 21-22 in Bergen's Grieg Hall. The conference will gather global, regional, and national leaders, practitioners, researchers, persons affected by the disease, and other stakeholders.

There will be sessions on medical and social aspects of leprosy as well as on history preservation. Special sessions, social and cultural side programs, and maybe a few surprises will add variety. There will also be a poster session, and we are working to attract sponsors in the hope that we will be able to cover travel and accommodation expenses for some contributors.

The evening before the conference officially opens, on June 20, Bergen municipality will welcome participants to a reception in King Haakon's Hall, a medieval banquet hall in the city center. On the first day of the conference, Bergen Leprosy Museum will host a "night at the museum."

Please visit our website at <https://hansen2023.org/>, and check the event information on page 8 of this issue of the *Leprosy Bulletin*. We look forward to hosting you in Bergen!



This well-known photograph of Hansen in his laboratory is part of the University of Bergen Library's Special Collections (<https://www.uib.no/en/ub/71766/our-special-collections-treasure>).

International Symposium at the Vatican on Hansen's Disease held in Rome in January

On Jan. 23-24, 2023, the International Symposium at the Vatican on Hansen's Disease was held at the Augustinian Patristic Institute (Augustinianum) in Rome on the theme "Leave No One Behind." The Symposium was co-hosted by the Fondation Raoul Follereau, Italian Association Amici di Raoul Follereau (AIFO), and Sasakawa Leprosy (Hansen's Disease) Initiative, in cooperation with the Dicastery for Promoting Integral Human Development, as part of the Initiative's "Don't Forget Leprosy / Don't Forget Hansen's Disease" campaign launched in 2021.

In addition to being part of the campaign, the event was conceived as follow-up to a symposium titled "Towards Holistic Care for People with Hansen's Disease, Respectful of Their Dignity" that was held at the same venue in 2016. Because of the COVID-19 pandemic, countries and organizations worldwide have struggled to provide the holistic care that was hoped for six-and-a-half years ago.

This year's symposium gathered around 130 health and human rights experts, organizational representatives, and persons affected by Hansen's disease (leprosy) or other neglected tropical diseases (NTDs), altogether from 24 countries, to discuss actions needed to achieve "zero leprosy" and realize a society in which no one is left behind.

Prayers and the reading of a written message from Pope Francis opened the event. Greetings from organizers and invited dignitaries followed, and included video messages from Volker Türk, UN High Commissioner for Human Rights, and Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization.

The morning of the first day ended with the launch ceremony for the 2023 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy. Initiated in 2006 by WHO Goodwill Ambassador Yohei Sasakawa in his role as chairman of The Nippon Foundation, the Global Appeal brings attention to leprosy-related discrimination and aims to generate momentum for an inclusive society. This year's Global Appeal declaration was endorsed by the organizers and participants of the Symposium and read by Miss World Brazil 2022, Letícia Cezar da Frota, who has been using her platform to act as an ambassador for the fight against Hansen's disease in her country.

In the afternoon, participants considered the theme "Toward Zero Leprosy" through two panel discussions, one focused on disease and disability and the other covering stigma and discrimination.

On the second day, the morning sessions addressed the broader theme of "Toward Realizing a Society in Which No One Is Left Behind." Participants heard directly from persons affected by leprosy, who described their experiences during the pandemic, and from leaders of religious organizations, who shared some best practices.

The final sessions of the two-day gathering offered "Recommendations and suggestions on how to move forward from the conclusions and recommendations adopted in 2016."

Goodwill Ambassador Sasakawa captured the overall message of the Symposium when he told participants that the COVID-19 pandemic must not be used as an excuse; everyone must work together to realize a world free of leprosy where no one is left behind.

Watch Symposium video recordings and read Global Appeal declaration:

<https://gasasakawa.org/globalappeal2023/>



The declaration from this year's Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy was read by Letícia Cezar da Frota, Miss World Brazil 2022.



Organizer representatives joined hands to symbolize their commitment to working together towards zero leprosy.

REPORT

Pope Francis calls for renewed commitment to building an inclusive society

“Pope,” meaning “father,” is the honorary title for the bishop of Rome, head of the Roman Catholic Church and Vatican City and leader of an estimated 1.3 billion Catholics worldwide. The current pope, born to Italian immigrants in Argentina, took the pastoral name “Francis” upon his election to the role in 2013. He is the first pope from the Americas and the first pope from south of the equator.

For the International Symposium at the Vatican on Hansen’s Disease, held Jan. 23-24, 2023, Pope Francis contributed a written message, which was read at the event’s opening by Sister Alessandra Smerilli F.M.A., Secretary of the Dicastery for Promoting Integral Human Development.

Here we share two selected quotations from the English translation:

“[W]e must seize the opportunity of World Leprosy Day to revise our models of development, and to denounce and try to correct the discrimination they cause. This is a fitting occasion to try to renew our commitment to building an inclusive society that leaves no-one at the margins.”

Specifically, we must ask ourselves how best to collaborate with people affected by leprosy, treating them fully as people, recognizing them as the key protagonists in their struggle to participate in fundamental human rights and to live as fully-fledged members of the community.”



WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa showing Pope Francis’s message just after it was delivered by Sister Alessandra Smerilli F.M.A., Secretary of the Dicastery for Promoting Integral Human Development.

Read Pope Francis’s message in full:

<https://press.vatican.va/content/salastampa/en/bollettino/pubblico/2023/01/23/230123a.html>



SPOTLIGHT

About the Dicastery for Promoting Integral Human Development

In his closing speech, Monsignor Charles Namugera noted that over the two days of the Symposium, some people would look at “Dicastery for Promoting Integral Human Development” on his name tag and ask, puzzled, what is that about?

A dicastery is a type of department within the Roman Curia, the central administrative body of the Catholic Church. The Dicastery for Promoting Integral Human Development was created by Pope Francis in 2016 to work on “issues regarding migrants, those in need, the sick, the excluded and marginalized, the imprisoned and the unemployed, as well as victims of armed conflict, natural disasters, and all forms of slavery and torture.”

As a representative of the Dicastery, Monsignor Namugera explained that “integral human development” is a “person-centered approach” that has roots in Pope Paul VI’s 1967 encyclical about the progress of people (*Populorum progressio*).

Monsignor Namugera connected the Church’s interest in integral human development to the theme of the Symposium:

leave no one behind. He praised the Symposium for bringing together various actors at various levels, emphasizing that “integral human development, or authentic development, cannot be done by one actor alone. It needs the concerted effort of people working at different levels from different angles in order to respond to the multi-dimensional needs of a human person.”



Monsignor Charles Namugera, Dicastery for Promoting Integral Human Development, giving the final speech during Day 2, Session 2: Perspectives of the Organizers.

What's next? Symposium voices on the issues and how to move forward

Ongoing need for awareness raising

Whenever I speak to anyone about leprosy there's always various responses that come, but there's one thing that is recurring, which is a sense of surprise that it still exists. No matter who I speak to, this is always predominantly the first thing that is said."



Arielle Cavaliero
Global Business Director
Leprosy Global Health Program at Novartis

We believe that raising awareness about leprosy in schools for young people between 10 and 15 years old and professionals in training in health areas is key for promoting consciousness and replicating knowledge . . . so that in fact we will be able to create a future without stigma and discrimination and that is sensitive to the needs of the most vulnerable."



Lucrecia Vasquez Acevedo
President
Felehansen (Colombia)

Involving persons affected by leprosy

Please listen to people affected by leprosy. This is the only way we can achieve a solution, because this is the only way we can really get to know the problems and come up with solutions to these problems."



Patrícia Gonçalves Soares
Executive Secretary
Morhan (Brazil)

My suggestion is that persons affected by leprosy should be included in government planning, in whatever schemes the government has. Persons affected by leprosy should be part of the process; not at the end of it, but throughout the process."



Maya Ranavare
President
Association of People Affected by Leprosy (India)

Changing laws and customs

In a report that I presented to the General Assembly, I identified the persistence of traditional non-written customs and practices that discriminate against persons affected by Hansen's disease and which are grounded on beliefs coming from world or local religions. Cooperating with religious leaders is indeed one important action we can undertake."



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

I think we've learned from other sectors like the HIV sector that the most effective advocacy is self-advocacy. . . . [Training] can be as simple as stuff like ensuring that people know what their rights are and what they're entitled to."



Brent Morgan
International Director
The Leprosy Mission International

Medical and technological innovation

Traditionally we've thought of prevention as being mainly case finding and treatment of cases with MDT. . . . Then there is a recent development of post-exposure prophylaxis with single dose rifampicin and that is being gradually rolled out. . . . Then future possibilities — a leprosy-specific vaccine, or LepVax."



Dr. Paul Saunderson
Technical Advisor
American Leprosy Missions

During the COVID lockdown period, telemedicine through audio and video calls by using WhatsApp and Zoom applications to connect with people in need of care was a very successful model which was applied across the world. . . . In addition, innovations of virtual teaching and learning methods made education and training accessible and relatable for people of different age groups, ethnicities, and locations."



Dr. P. Narasimha Rao
President
International Leprosy Association

Leveraging NTDs network

When I reach out to a community for a case of leprosy, for instance, I am faced with so many difficulties. But then when it comes to treating skin conditions, it often happens that I can also identify leprosy cases. And this is why WHO has launched the integrated strategy on NTDs with skin manifestation."



Dr. Roch Christian Johnson
Medical Director
Fondation Raoul Follereau

The second thing I would like in this slogan [leave no one behind] is the integration with other entities together so our reach will be very high. At LEPRO, we integrated in 2008 with lymphatic filariasis for two reasons: stigma reduction and also people should come together and they can act together."



Rajni Kant Singh
State Coordinator for Bihar Operations
LEPRO Society (India)

Audience with Pope Francis

On Jan. 26, 2023, while in Rome to attend the International Symposium at the Vatican on Hansen's Disease, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa had an audience with Pope Francis at the Apostolic Palace in Vatican City.

After thanking the Pope for the message that he wrote to Symposium participants and for the cooperation of the Holy See's Dicastery for Promoting Integral Human Development, the Goodwill Ambassador conveyed news of the Symposium's success. He expressed his hope for a future opportunity to update the Pope on the progress of leprosy elimination activities, especially considering the large number of Hansen's disease patients in South America, where there are many members of the Catholic Church. The Pope answered graciously that the door is always open.

The Goodwill Ambassador took the opportunity to inform the Pope about the stigma and discrimination that still exist today, including discriminatory laws and harsh living conditions. In response, the Pope acknowledged that the fight against leprosy continues in Argentina, where he was born and lived most of his life. He highlighted the Catholic Church's activities and expressed gratitude for the Goodwill Ambassador's efforts. He also stated that leprosy is a curable disease and noted that curability should motivate everyone to actively engage in case-finding activities.

Based on knowing that the Pope had visited Japan in 2019, the Goodwill Ambassador asked him about his most salient memory. The Pope spoke of visiting Nagasaki and brought

out the photograph that he had made into a postcard just before the Catholic Church's World Peace Day on Jan. 1, 2018. The photograph, taken in the aftermath of the atomic bombing, shows a young boy carrying his dead younger brother on his back, waiting for his turn at a cremation site. The postcard included the words "*il frutto della guerra* (the fruit of war)" and the Pope's signature. During the conversation, he said strongly that war is a tragedy and must not be repeated.

The Goodwill Ambassador shared his personal experience of the Tokyo firebombing. He was six years old at the time and, along with his bedridden mother, miraculously survived the living hell of seeing people screaming and dying from the flames. He thinks of this experience as the origin of his current humanitarian activities.

The Catholic Church has over 1.3 billion members worldwide and operates about 5,000 hospitals and 15,000 health centers, mainly in developing countries, as well as more than 500 leprosy sanatoriums. Pope Francis's supportive words and open door raise hopes for ongoing cooperation towards a leprosy-free world.



At the end of the audience, Pope Francis presented a commemorative medal to each attendee (Apostolic Palace, Vatican City, Jan. 26, 2023). © Vatican Media



Pope Francis kindly accepted the Goodwill Ambassador's request for a photo with the "Don't Forget Hansen's Disease" banner (Apostolic Palace, Vatican City, Jan. 26, 2023). © Vatican Media

WISH LIST



Pragnya Ayyagari
Miss Supranational India 2023

In November 2022, Pragnya Ayyagari was one of two beauty pageant winners to be invited to attend the 2nd Global Forum of People's Organizations on Hansen's Disease held in Hyderabad. She will represent India at the Miss Supranational 2023 competition in Poland later this year.

The *Leprosy Bulletin* occasionally asks a person affected by leprosy or an individual involved in leprosy-related work for a list of things that they wish could happen. We ask contributors to be bold in order to stimulate thinking and inspire new approaches.

- 1** I wish for more support for young people affected by the disease to share their perspectives so that children can learn from their peers.
- 2** I wish for a world where everyone accepts Hansen's disease as any other disease and discrimination against persons affected by the disease is eliminated.
- 3** I hope that the disease is detected and treated at an early stage to prevent disabilities.
- 4** I wish for persons affected by the disease to get equal job opportunities and live a good life.

ANNOUNCEMENT

Event schedule for 150th Anniversary of Hansen's discovery



150 years
Discovery of the
Leprosy Bacillus 1873

At the end of February, Norway's University of Bergen, in collaboration with the Sasakawa Leprosy (Hansen's Disease) Initiative, will host events that commemorate and prompt reflection on Gerhard Armauer Hansen's discovery of the leprosy bacillus in 1873.

Please see page 3 of this issue of the *Leprosy Bulletin* for additional details provided by the head of the organizing committee, Magnus Vollset.

Commemorative event (Feb. 28, 2023)

Location: University Aula, Bergen, Norway

Time: 11:00 a.m.–12:30 p.m. CET

Registration: <https://www.uib.no/en/ledelsen/157014/armauer-hansen-2023-anniversary>



Webcast (Feb. 28, 2023)

Location: online

Time: 1:00 p.m.–2:15 p.m. CET

Registration: https://us06web.zoom.us/webinar/register/WN_sXOFFt1ZSyqecHY2CHCjYQ



Conference (June 20-22, 2023)

Location: Grieg Hall, Bergen, Norway

Registration: <https://hansen2023.org/hansen-anniversary-conference/>



SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE

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