WHO GOODWILL AMBASSADOR'S

LEPROSY BULLETIN

NO. 121 JUNE 2024

Take advantage of our window of opportunity

Message from the ambassador

I have compared the fight against leprosy to a motorcycle, with the front wheel representing efforts to control the disease and the back wheel indicating actions to eliminate discrimination. As the Goodwill Ambassador, I try to keep both wheels moving. I also leverage my roles as the Chairman of The Nippon Foundation and the Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy to accelerate progress.

Next year, 2025, will mark 50 years since The Nippon Foundation (TNF) and the Sasakawa Health Foundation (SHF) began supporting national leprosy programs through the World Health Organization (WHO). To date, the foundations have given approximately US$200 million, but more than the amount, I think that it is the consistency of support, maintained over half a century, that has made a difference. Humanity is now closer than ever to ending leprosy.

Unfortunately, in many countries, the motorcycle stalled during the COVID-19 pandemic. To pick up the pace again, ministries of health will have to redouble their efforts. I will be thinking about how I can use my position as Goodwill Ambassador to help them.

To gather momentum for the last mile, the *Leprosy Bulletin* is kicking off a six-part series featuring experts from various fields who have worked with TNF/SHF in the past. In addition to asking them to share their memories, the *Bulletin* is soliciting their ideas about what needs to happen now in order to achieve a leprosy-free world. I hope you will join me in heeding the call of our first expert, Dr. David Heymann, to take advantage of our "window of opportunity."

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. David Heymann
Professor, London School of Hygiene and Tropical Medicine

Dr. Koichi Suzuki
Professor, Teikyo University

Dr. Alice Cruz
former UN Special Rapporteur

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

50th Anniversary of WHO–TNF/SHF Partnership

Special series to recognize 50-year partnership

With this issue, the *Leprosy Bulletin* is launching a six-part series in relation to the upcoming 50th anniversary of the partnership between the World Health Organization (WHO) and The Nippon Foundation (TNF)/Sasakawa Health Foundation (SHF) for the elimination of leprosy.

The partnership began in 1975 when Ryoichi Sasakawa, the first chairman of TNF and co-founder of SHF, donated US$1 million to WHO to eradicate the disease worldwide. For five years (1995–1999), TNF provided WHO with US$10 million per year so that multidrug therapy (MDT) could be distributed to all patients free of charge. Yohei Sasakawa has been the WHO Goodwill Ambassador for Leprosy Elimination since 2001.

Based on the theme of partnership and collaboration, the series will feature people who have worked closely with TNF/SHF over the past 50 years. The *Bulletin* will ask them to reflect on their experiences with the foundations and to share their thoughts on the place of TNF/SHF in the global fight against leprosy.

Ryoichi Sasakawa (left) stands with Dr. Halfdan Theodor Mahler (right) at an event in Tokyo. Dr. Mahler served three terms as the Director-General of the World Health Organization from 1973 to 1988. The flag of Denmark in the background acknowledges Dr. Mahler's nationality.

Interview with Dr. David Heymann

Dr. David Heymann is currently Professor of Infectious Disease Epidemiology at the London School of Hygiene and Tropical Medicine and a Distinguished Fellow at the Centre on Health Security at Chatham House, London. From 1988 to 2009, he was based at WHO headquarters in Geneva, on secondment from the Centers for Disease Control and Prevention in the United States. For five years of his time with WHO, from 1998 to 2003, he had overall responsibility for WHO's leprosy program as the Executive Director of the Communicable Diseases Cluster. He held this post at a time when WHO was working to eliminate leprosy as a public health problem at the global level by the year 2000, based on a resolution adopted by the 44th World Health Assembly in 1991.

LB (*Leprosy Bulletin*)**: When did you join the World Health Organization (WHO), and in what capacity?**

DH (Dr. David Heymann)**:** I joined WHO in 1988. After 13 years in Africa and two years in India, I was seconded from the Centers for Disease Control (CDC) in the United States. First I worked on the AIDS program, and then in 1995 I was asked by the Regional Director in Africa to help out with the Ebola outbreak, because I had been at the first and second outbreaks, and this was the third. When I came back, the Director General (DG) asked me to set up a new program on emerging infections. Two years later, I became Executive Director of Communicable Diseases under a new DG, Gro Harlem Brundtland. At that time, the leprosy program came under my mandate. That was in 1998.

LB: What was your first encounter with TNF/SHF?

DH: It was through a director who worked for me, Dr. Maria Neira. She knew Mr. Sasakawa [Yohei Sasakawa, the current Goodwill Ambassador] quite well, and she introduced me to Dr. Yuasa [Yo Yuasa, medical director of SHF], and I was then invited to the annual meeting of SHF in Japan. There I met Mrs. Kay Yamaguchi, Professor Kenzo Kiikuni, Mr. Tatsuya Tanami [executive director of TNF], and Mr. Sasakawa.

LB: What was your impression of TNF/SHF?

DH: I think they were a real engine for the leprosy control program and that they were an engine that moved WHO towards stronger leprosy control through various means,

including World Health Assembly resolutions. They were very important in calling attention to leprosy through whatever they did.

LB: This was the era of the Global Alliance for the Elimination of Leprosy (GAEL), which was formed in 1999 to maintain the momentum against leprosy beyond 2000 and to help all countries eliminate the disease as a public health problem. GAEL eventually disbanded in 2003 due to disagreements among its members. What are your memories of that time?

DH: There was quite a bit of tension in the program. TNF [1995–1999], and later Novartis and the Novartis Foundation [2000–present], were providing medications at no cost. There were other NGOs that were also providing medications. Medications seemed to be the key to fundraising for these NGOs, and so when these donations began, they were not very happy. That created some tension. There was also tension over who should lead the program, and who should not, and I think there was quite a bit of resentment from some of the NGOs toward the WHO. I saw my role as trying to mediate the many tensions that were occurring. But tensions often develop, and the only way to deal with them is to sit around the table with everyone.

LB: The WHO–TNF/SHF partnership will be 50 years old in 2025. What do you think has contributed to its longevity?

DH: To me it was a clear, constant and unwavering vision that drove the partnership. TNF/SHF had a vision. It changed over time: as I understand it, initially it was based purely on treatment and diagnosis; then it became more about human rights and people affected by leprosy, or Hansen's disease, adding an important element to the already important work of providing for diagnosis and treatment.

Mr. [Yohei] Sasakawa has been a real champion for leprosy elimination and has been able to meet with very influential people, including heads of state, all over the world. He is an amazingly dynamic and energetic leader who has done many good things and continues to generate the energy behind the leprosy program.

LB: Do you think it is unusual for private-sector partners to support a single disease program for so long?

DH: There are others. In polio eradication, there is Rotary International. It has been a faithful partner since 1988. There is the onchocerciasis (river blindness) partnership, which depends on the Mectizan Donation Program, supported by the Merck Foundation. So the Sasakawa foundations' partnership with WHO is not unique, but it's very important, especially given that leprosy is often neglected because it is a high disability disease, as opposed to a high mortality disease or an emerging infection, and high disability diseases don't tend to attract a lot of donor financing.

LB: In their partnership with WHO, TNF and SHF have always attached importance to having numerical targets in the fight against leprosy. What are your views on targets?

DH: Having targets that say this is going to happen, and this is going to happen by a certain date or this is what we are aiming for makes it possible to pull in short-term partners to provide drugs, whether for leprosy or for onchocerciasis or other diseases. But long-term sustainability is really important to think about at the same time. I used to wonder, and I still do, what would happen if there was a decision by Novartis or TNF/SHF to stop contributing to leprosy control. I don't believe that WHO would be able to continue on its own because of many competing priorities, especially those with high mortality.

LB: How do you view the progress made against the disease and the prospects for the future?

DH: I like to talk about windows of opportunity, and I think there is a window of opportunity to really reduce the prevalence and incidence of leprosy to a very low level, where it could theoretically disappear in the future. However, it is important to take advantage of this window of opportunity now when it exists. The same applies to any other disease. If there is a window of opportunity because all the parts fall in place as they have for leprosy, it is important to take advantage of it and hope that the window remains open long enough to have an impact.

Dr. David Heymann (seated at table, far right) attended the "First Meeting of Global Alliance for Elimination of Leprosy & Advocacy," held in New Delhi, India, Jan. 30–31, 2001, as the WHO Executive Director of Communicable Diseases. According to a report published at the time, Dr. Heymann emphasized that, in addition to integrating leprosy into general health services and teaching health workers at all levels to diagnose and treat leprosy, all available techniques should be used to encourage communities to demand their right to live in a world without leprosy.

VIEWPOINT

Dr. Koichi Suzuki
Professor, Department of Clinical Laboratory Science
Faculty of Medical Technology, Teikyo University

Professor Suzuki is a basic scientist in the field of leprosy and other neglected tropical diseases. Before moving to Teikyo University, he served for 15 years as chief of the Laboratory of Molecular Diagnostics at Japan's National Institute of Infectious Diseases.

https://plaza.umin.ac.jp/suzuki-lab/

CRADAR-i method promises a breakthrough in point-of-care diagnostic testing for leprosy

At present, definitive leprosy diagnosis relies on laboratory-based PCR testing involving expensive equipment, refrigeration, and highly trained technicians. Testing for drug resistance requires an additional scientific instrument called a DNA sequencer. Access to these resources is limited in many parts of the world, and so many persons affected by leprosy have no choice but to accept inadequate diagnosis and inappropriate treatment.

A research team that I lead along with Assistant Professor Kei Mikita of Keio University and Senior Researcher Hiroyuki Miyamura of the National Institute of Advanced Industrial Science and Technology is trying to change this situation. With support from the Sasakawa Health Foundation and others, we are developing a method that can be used for diagnostic testing at point of care in resource-limited settings. We call it the CRADAR-i method.

With this method, we can provide all the necessary reagents for DNA amplification and detection within a small device that does not require refrigeration. Device kits are easily portable and can be stored for up to one year at ambient temperature in tropical environments. Operation is simple: Just drop in a sample and press a few buttons. Results appear within one hour in the form of a blue line visible to the naked eye. Compared to conventional PCR and DNA sequencing methods, the CRADAR-i method reduces cost of detection while maintaining sensitivity.

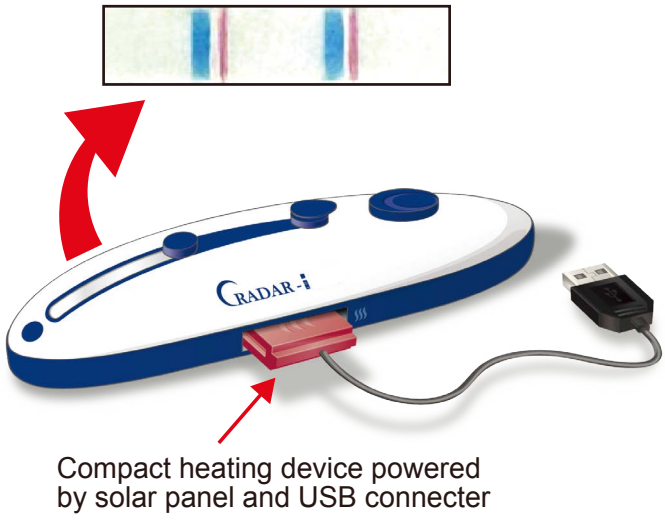
Testing for *M. leprae* and rifampicin-resistant strains

We can configure a CRADAR-i device so that it detects *Mycobacterium leprae* as well as mutations that confer resistance to the drug rifampicin. Instead of diagnosing leprosy based on patient history and physical examination only, or waiting days for results from a laboratory, healthcare providers will be able to test immediately for *M. leprae* and make a same-day definitive diagnosis. They will also be able to make decisions about antimicrobial therapy and post-exposure prophylaxis (PEP) based on evidence of susceptibility. This latter point is especially important in the context of the World Health Organization's recommendation to administer single-dose rifampicin post-exposure prophylaxis (SDR-PEP) to close contacts to prevent transmission. Rifampicin susceptibility is a minimum requirement for the success of this strategy.

Working to make the devices available

In 2022, we shared a report about the CRADAR-i method at two events in India: the International Leprosy Congress in Hyderabad (Nov. 8–11) and the "Workshop on strengthening laboratory testing procedures for antimicrobial resistance (AMR) surveillance in leprosy" organized by WHO in Karigiri (Nov. 14–15). As of June 2024, we have confirmed that CRADAR-i works well in the laboratory. The next step is to recruit partners to mass produce device kits and make them available worldwide either free of charge or at very low cost.

The CRADAR-i method addresses major challenges affecting leprosy diagnosis, treatment, and prevention of transmission. We expect that field-deployable devices using the CRADAR-i method will play a crucial role in helping WHO achieve its zero leprosy goals.



Schematic illustration of a device that uses the CRADAR-i method. The device is small, self-contained, and easy to operate. When *Mycobacterium leprae* is detected, a blue line appears within one hour. Devices with multiplexing capability for detecting drug-resistant mutations have additional features.

VIEWPOINT

Dr. Alice Cruz
Program Advisor for Human Rights Issues, Sasakawa Health Foundation
Former UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members

Dr. Alice Cruz held the mandate for UN Special Rapporteur from when it was first established by the Human Rights Council in 2017 until the end of her second three-year term in 2023.

A rights-based perspective on stopping transmission

Last month, in May 2024, I attended the Global Partnership for Zero Leprosy (GPZL) Zero Transmission Symposium to discuss the interruption of Hansen's disease and take stock of progress made since a similar symposium was held 10 years ago.[1] Based on my field of expertise, I view the problem of transmission from a human rights perspective. Here, I am sharing some of what I noticed in the hope that this perspective will be included in all discussions of ways to prevent transmission.[2]

The question of how to stop transmission has been at the center of scientific discussions about Hansen's disease for 150 years. While I acknowledge the vitality of ongoing scientific research regarding this question, I also believe that merely scientific or technical responses are inadequate. Limited allocation of funds by governments and the feeble implementation of adequate policies and strategies by national healthcare systems, especially in remote and marginalized subnational areas, play an important role in transmission – and those issues are of a political nature.

Compared to the symposium held 10 years ago, the participation of three representatives of persons affected by Hansen's disease marked a step forward in the direction of guaranteeing that persons affected by Hansen's disease enjoy the right to a voice and choice in discussions about stopping transmission. However, more significant participation from a wider set of their organizations could have been enabled. Partnerships between scientists and persons with lived experience of a specific disease have proven to be successful in other fields, and I am convinced that organizations of persons affected by Hansen's disease have a big role to play in research, policy-making, and accountability.

I consider the inclusion of social determinants of Hansen's disease in the program to be another step forward. The symposium showed that more efforts are required for understanding the mechanisms through which the denial of economic and social rights, such as access to decent housing, clean water, and a minimum standard of living, contribute to transmission.

The symposium pinned most of its hopes for progress on post-exposure prophylaxis (PEP).[3] It is of the essence that PEP's implementation is guided by international human rights law in order to avoid any potential double standards. There are legal provisions in regards to the right of access to information and informed consent that should be duly guaranteed. Organizations of persons affected by Hansen's disease can play a very important role in human rights monitoring of PEP programs.

Lastly, while I respect that "zero transmission" was symposium's topic, I cannot help but wonder if discussions about stopping transmission should not also include deeper consideration of how to guarantee the continuum of care (including, among other things, adequate treatment of reactions; monitoring of nerve damage during medical treatment and after bacteriological cure; access to secondary and tertiary care; provision, free of charge, of assistive devices; rehabilitation and reconstructive surgery) as the latter should not be sidelined while the goal of stopping transmission has not been reached.

Echoing what I have been hearing from persons affected by Hansen's disease for many years, I would like to leave readers with the following question: Do we know enough about how to stop human suffering associated with Hansen's disease? Perhaps, in the future, there could be a symposium to discuss this question.

Participants at the GPZL Zero Transmission Symposium 2024, hosted by the University of Bergen, stand ready to begin Day 2 (Bergen, Norway, May 23–25, 2024).

[1] For more information about the GPZL Zero Transmission Symposium, see https://hansen2023.org/zts24/9.

[2] All opinions expressed in this article are my sole responsibility.

[3] Specifically, single-dose rifampicin post-exposure prophylaxis (SDR-PEP).

AMBASSADOR'S JOURNAL

Goodwill Ambassador seeks cooperation to realize WHO's global strategy targets by 2030

The World Health Organization (WHO) Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa, visited Geneva, Switzerland, to meet with health ministers from WHO-designated global priority countries and other officials who were in the city to attend the 77th World Health Assembly. He inquired about each country's leprosy situation and acknowledged the setbacks that happened during the COVID-19 pandemic. He requested that each country accelerate their efforts to reach WHO's targets by 2030.

When meeting with health leaders from Africa, the Goodwill Ambassador spoke of climbing Mt. Kilimanjaro earlier this year and raising the "Don't Forget Leprosy (Hansen's Disease)" banner at the summit. He drew parallels between the determination that it took to make the ascent at age 85 and his commitment to supporting the fight against leprosy on the continent.

For administrative and reporting purposes, WHO organizes the world's countries into six regions. The 23 countries that WHO has designated "global priority" for leprosy are located in five of these regions: Africa (11), South-East Asia (6), Western Pacific (3), Eastern Mediterranean (2), and Americas (1). The two Eastern Mediterranean countries, Egypt and Somalia, are on the African continent and are members of the African Union. The Goodwill Ambassador's desire to intensify his activities in Africa is related to the fact that over half of the global priority countries (13) are located on the continent.

The Goodwill Ambassador reported to WHO Director-General Dr. Tedros Adhanom Ghebreyesus that he successfully reached the summit of Mt. Kilimanjaro, as he had promised to do when the two leaders met at the Global Appeal in January. He affirmed that he plans to show the same follow-through on his commitment to increasing activities in Africa.

Africa (continent)

Ms. Minata Samate Cessouma, Commissioner for Health, Humanitarian Affairs and Social Development, African Union

The Commissioner acknowledged that leprosy is a very important issue. She noted that the disease is present in her village and she recalled seeing people with hand and foot deformities. She was also aware of discrimination, and agreed on the importance of spreading correct information so that cases can be found quickly and treated promptly. Reflecting on the COVID-19 pandemic, she observed that the fear and discrimination seen during the period when the disease was least understood might have something in common with the ways that people respond to leprosy when they do not have accurate knowledge about it.

Dr. Mekdes Daba, Minister of Health, Ethiopia

The Minister affirmed Ethiopia's commitment to moving towards zero leprosy. The country has made progress in control of the disease, but the number of new cases is increasing and discrimination is deep-rooted. The Ministry of Health is seeking to address leprosy from all angles, including research, patient services, and community support.

Dr. Bernard Okoe-Boye, Minister of Health, Ghana

In Ghana, new leprosy case numbers have stabilized at 260–280 cases per year since 2017,[1] and so WHO has not designated it a WHO global priority country. As patient numbers drop, it is easy to "forget" leprosy, and so the Goodwill Ambassador was pleased to meet with the Minister and hold the "Don't Forget Leprosy" banner together.

Dr. Armindo Daniel Tiago, Minister of Health, Mozambique

The Minister confirmed that the number of leprosy patients in Mozambique has been increasing in recent years. In the area that he is from, a local organization has been providing support to the many patients, but this support is scheduled to end in the near future. With situations like this in mind, he agreed on the importance of the government's efforts.

Dr. Ali Haji Aden, Minister of Health, Somalia

Somalia believes in the integration of health services. The Ministry of Health is working with the WHO Country Office to combat leprosy under the umbrella of Neglected Tropical Diseases (NTDs). Discussions with the director in charge of polio are exploring similarities in required services.

The Minister acknowledged the severity of the stigma attached to leprosy. He noted that Somalia lacks centers for leprosy treatment, and as a result, there are not enough opportunities for disseminating accurate information about the disease. Since 2016, the number of new patients has risen from about 800 to 2,000. Leprosy patients often live in isolated communities, and developing adequate measures to reach them continues to be a challenge.

South-East Asia

Dr. Samanta Lal Sen, Minister of Health and Family Welfare, Bangladesh

The Minister, who assumed his post in January of this year, has direct experience helping leprosy patients with disabilities through his work as a plastic surgeon and burn specialist. He affirmed that, in line with WHO's global leprosy strategy for 2021–2030, Bangladesh aims to achieve zero leprosy by 2030. He is eager to eliminate stigma and discrimination against persons affected by leprosy, and spoke positively about cooperating with the Goodwill Ambassador.

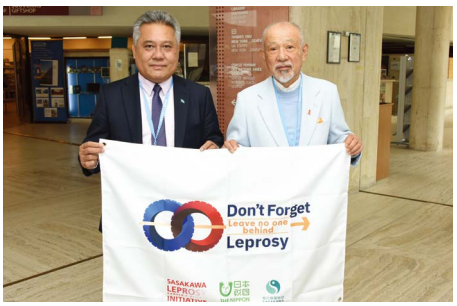
Mr. Budi Gunadi Sadikin, Minister of Health, Indonesia

The Minister spoke of Indonesia's successes and challenges. A good system of leprosy screening has been established, cases are being identified, and medical care is in place. However, after patients are diagnosed, it is difficult to ensure that they continue to receive and take their medication.

Western Pacific

Mr. Ota Kisino, Minister of Health and Human Services, Marshall Islands

The Minister reported that screening for leprosy has been completed in Majuro and Ebeye Island, the two most densely populated parts of the country. The Marshall Islands is composed of approximately 1,225 islands and islets spread out in two chains. Completing screening of all settled areas will take more time.



Mr. Marcus Samo, Secretary of the Department of Health and Social Affairs, Micronesia

The Secretary explained that the leprosy situation in Micronesia is challenging and not improving as rapidly as he had hoped. However, he believes that change is possible, and he hopes that the Goodwill Ambassador will be able to make an official visit so that they can discuss the situation in greater depth. Micronesia wants to make every effort to reduce the number of people affected by leprosy.

[1] https://ilepfederation.org/zero-is-possible/

SPOTLIGHT

New website about Bergen's leprosy heritage

In the global history of leprosy, Norway's second largest city, Bergen, is best known for being the place where Dr. Gerhard Armauer Hansen discovered the bacillus *Mycobacterium leprae* in 1873. The city is also the setting for the largest concentration of leprosy patients in Europe during the latter half of the nineteenth century. In the 21st century, many have forgotten how the disease affected the people of western Norway and shaped Bergen into a hub for leprosy-related research and public health innovation. A new website by Bergen City Museum (Bymuseet i Bergen), supported by the Sasakawa Health Foundation, aims to make the full history of Bergen's experience with leprosy accessible online.

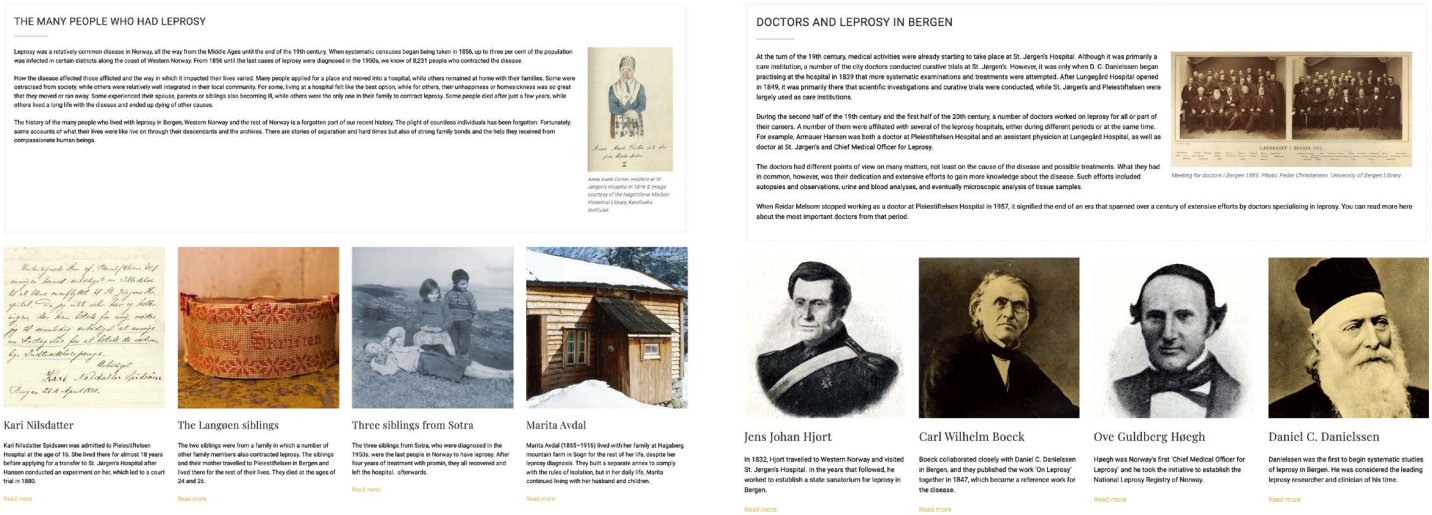
Launched in 2023 along with a number of events marking the 150th anniversary of Dr. Hansen's discovery, the comprehensive website shares "Bergen's Leprosy Heritage" through photographs, written descriptions, video interviews, and interactive 3D models of buildings and exhibits. Content in Norwegian still exceeds content in English, but translation is underway, and the final version of the website will be fully bilingual.

People familiar with Bergen may note that the city already has a physical museum for leprosy heritage based in the preserved buildings of St. Jørgen's Hospital. With regular opening hours only during the summer months and 300-year-old buildings without universal accessibility, The Leprosy Museum (Lepramuseet) can be challenging to visit in person. The new website offers a way to tour the former hospital and explore exhibits virtually.

The website also introduces visitors to the Leprosy Archives of Bergen, which include materials from the city's three leprosy hospitals – St. Jørgen's, Pleiestiftelsen, and Lungegård – as well as documents kept by the Chief Medical Officer for Leprosy. High resolution images of selected materials along with descriptive text help visitors to understand why these archives are considered heritage of humanity and registered with UNESCO's Memory of the World Program.

Bergen's experience with leprosy shows the value of a scientific approach to disease while also calling attention to the need to consider effects on social relations and individual human dignity. Bergen City Museum offers the new website with respect for persons affected by leprosy and their family members and with the hope that the story of leprosy in Bergen will help to dispel myths about the disease that still affect people living today.

Bergen's Leprosy Heritage website:
https://www.lepra.no/en/home-en/



Bergen City Museum's new website titled "Bergen's Leprosy Heritage" provides a holistic picture of the city's experience with the disease. Through photographs, descriptive text, and 3D models, visitors can learn about how the people of western Norway responded to leprosy in the latter half of the nineteenth century.

SASAKAWA LEPROSY HANSEN'S DISEASE INITIATIVE

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