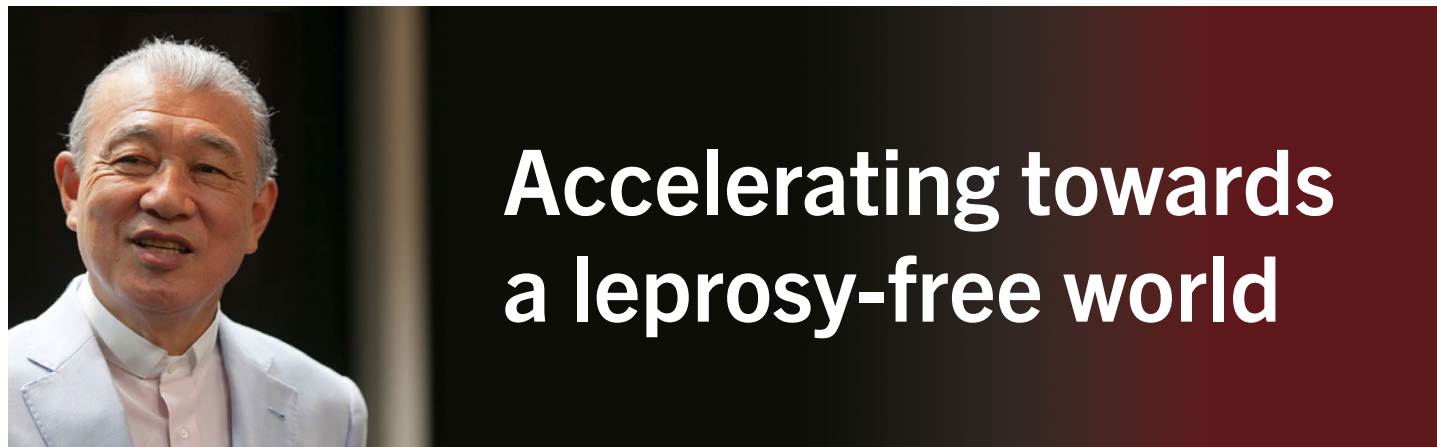


LEPROSY BULLETIN

NO. 114 APRIL 2023



Message from the ambassador

In Brazil, as of January of this year, Luiz Inácio Lula da Silva is once again president, and I would like to begin by offering my heartfelt congratulations to him on his inauguration. I have met with President Lula several times in the past, and he is one of the few leaders in the world with a deep understanding of leprosy. Law 11,520/2007, which provided for the granting of special pensions to persons affected by Hansen's disease who were subjected to compulsory isolation and hospitalization, was promulgated under his previous administration.

Although Brazil has never achieved WHO's goal of "elimination as a public health problem," I hope that under President Lula's leadership significant progress will be made in detecting and treating cases and in fighting stigma. I will do what I can to accelerate the progress.

I have started by supporting the resumption of preparations for a national summit. The purpose of the summit is to bring together the president; relevant ministers; governors and mayors of endemic states; medical personnel from all over the country; persons affected by Hansen's disease; NGOs; and researchers to discuss a grand design for elimination of the disease. The summit was scheduled to be held at the end of March 2020, but had to be postponed at the last minute because of the coronavirus pandemic.

In March, I sent letters to President Lula and to Ministry of Health officials requesting that discussions regarding the summit resume. I received positive responses, and I hope that the summit will indeed be held and serve as a catalyst for the elimination of Hansen's disease in Brazil.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Claudio Guedes Salgado

Ministry of Health (Brazil)

Dr. Patrícia Duarte Deps

Ministry of Health (Brazil)

Dr. Marcos Vinicius Soares Pedrosa

Ministry of Health (Brazil)

Dr. Nesio Fernandes de Medeiros Junior

Ministry of Health (Brazil)

Cristina Nogueira

CulturAge (Portugal)

Maya Ranavare

APAL (India)

Al Kadri

PerMaTa (Indonesia)

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

VIEWPOINT

**Dr. Claudio Guedes Salgado**

Coordinator of Transmissible Diseases Care
Dept. of Integrated Care Management

Primary Health Care Secretariat
Ministry of Health (Brazil)

**Dr. Patrícia Duarte Deps**

Special Advisor for the Coordination of
Transmissible Diseases Care
Dept. of Integrated Care Management

Primary Health Care Secretariat
Ministry of Health (Brazil)

**Dr. Marcos Vinicius Soares Pedrosa**

Director
Dept. of Integrated Care Management

Primary Health Care Secretariat
Ministry of Health (Brazil)

**Dr. Nesio Fernandes de Medeiros Junior**

Secretary

Primary Health Care Secretariat
Ministry of Health (Brazil)

Brazil's contribution to a new era of Hansen's disease (HD, leprosy) control

Since the advent of multidrug therapy (MDT) in the 1980s, the peak of new Hansen's disease cases diagnosed in a year was 804,357 in 1998.¹ On May 13, 1991, during the 11th plenary meeting of the 44th World Health Assembly, participating countries agreed to set a goal of eliminating HD as a public health problem (with a prevalence of less than 1 case per 10,000 population) by the year 2000.² After the agreement, with support from the World Health Organization (WHO), the most endemic countries intensified capacity-building for diagnosing and treating HD, resulting in an increment of about 26% on the new case detection rate in seven years.³

In 1999, the number of new cases in the world was 738,112, a percentage decrease of almost 10% compared to the number the year before at the 1998 peak. Fifteen years later, in 2013, the number of new cases reached 215,656, a percentage decrease of over 70%.⁴ Within this fifteen-year period, a 61.16% percentage decrease occurred in just the 5-year period from 2001 to 2005, when the number of new cases dropped from 763,262 to 296,499.⁵ These dramatic decreases in the number of new cases occurred within fifteen years or less despite Hansen's disease being a chronic infection by a very slow-growing bacteria that has an incubation period that may reach 30 years or more.⁶ After India declared elimination in 2005,⁷ Brazil remained the only big country that did not reach WHO's HD elimination target.

Although the huge decrease of 2001–2005 was celebrated as a worldwide victory for persons affected by Hansen's disease, various real-life surveys reported 10 to 17 times more cases than officially reported,^{8–11} and 2015 mathematical models predicted that in 2020 there would be more than 4 million people with HD waiting to be diagnosed.¹² These numbers indicate that, instead of a true

decrease, the reduction of new cases per year may be a result of operational problems, such as the loss of expertise for diagnosing HD and/or the belief that HD does not exist anymore. The roughly 40% loss of diagnosis during the 2020–2023 COVID-19 pandemic is considered a disaster for HD control.¹³ This should make us think twice about the celebratory response to the approximately 60% percentage decrease in the number of new cases diagnosed 2001–2005. Instead of elimination of the disease, we have been seeing elimination of the diagnosis.

This “elimination of HD diagnosis” urgently requires recognition as a public health problem. Rather than pursuing a highly charged and contentious agenda around the “elimination” of HD, we should revise our strategy based on humanistic, scientific, and technological perspectives. This revised strategy would enable us to reach a larger population through the highly effective primary health care network, supported by health systems committed to providing comprehensive care and ensuring visibility and diagnosis.

We need to adopt a humanistic approach that engages in dialogue with social movements and focuses on the individual to redefine the perception of HD collectively. Our objective should be to fight prejudice and stigma prevalent in both the community and state structures, including health facilities and personnel. This humanistic approach would help to prevent unnecessary pain and suffering and utilize our knowledge, science, and technology to their fullest potential. Furthermore, we need to engage in extensive discussion around the concept of “cure” to prevent disappointment for both health professionals and HD patients, while encouraging debates on developing new therapeutic approaches for addressing bacterial elimination, nerve degeneration, and psychological challenges related to HD.

Currently, Brazil is focusing on a primary health care-based approach that leverages the expertise of general and family doctors for both diagnosis and clinical issues, alongside training for health professionals' teams. Through the "Mais Médicos" program, which allows for the direct training of 30,000 doctors, we aim to increase the capacity of the health system to diagnose cases and bring visibility to the issue of Hansen's disease as a neglected public health problem.

We plan to invest in the training of new hansenologists and introduce new laboratory tools for community surveillance and diagnostic confirmation, such as SSS for RLEP qPCR, to increase the reliability of diagnosis. There is also a need for complementary tools to supplement clinical findings, such as ultrasound, which has proven effective in identifying thickened nerves in contacts before clinical signs appear. After more than 40 years of MDT, new antibiotics with proven efficacy against *Mycobacterium leprae* must be made available to those who cannot tolerate MDT or are resistant to its drugs. The current lack of drugs for treating HD nerve degeneration is unacceptable and reflects the stigmatization faced by the neglected population living with HD. Additionally, recognizing that reactions may indicate the presence of live or multiplying bacilli, new approaches to treat them are also necessary.

Finally, an unknown number of persons affected by Hansen's disease living with disabilities need to be found and treated for their incapacities. Prostheses, orthotics, and surgery must be readily available to them, together with the necessary physical therapy and mental health to improve their quality of life.

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Secretary of Primary Health Care Nesio Fernandes de Medeiros Junior making a presentation about Brazil's primary health care challenges.

ANNOUNCEMENT



Cristina Nogueira
Chief Executive Officer, CulturAge

Cristina Nogueira is a historian and archivist based in Coimbra, Portugal. Under the trademark CulturAge, she develops heritage preservation and curation projects. CulturAge has been collaborating with the Centro de Medicina de Reabilitação da Região Centro - Rovisco Pais (CMRRC-RP) since 2017.

<https://www.culturage.pt/>

HCRP Museum's Scientific Library opened in March

The Hospital Colónia Rovisco Pais (HCRP) was established in 1947 in the Cantanhede municipality of Coimbra, Portugal, as a therapeutic village for around 1,000 inpatients. Until 1976, it was the epicenter of the country's fight against Hansen's disease. It guaranteed assistance to around 2,800 known Hansen's disease patients through its internal and external medical and social services.

In addition to assisting patients, the HCRP also had the mission of studying Hansen's disease, which it pursued through clinical and laboratory practice, participation in congresses on clinical trials, publication of scientific articles, and management of an indispensable library for informed clinical activity. The scientific dynamics that characterized the time as well as the activities of the HCRP were captured in *Rovisco Pais: Revista Portuguesa da Disease de Hansen*, a journal published between 1962 and 1981. Purchases and gifts from leprologists around the world enriched HCRP's library, which functioned as a global repository for leprosy-related knowledge and scientific research.

Since 2017, the Centro de Medicina de Reabilitação da Região Centro-Rovisco Pais (CMRRC-RP), with the support of the Sasakawa Health Foundation (SHF), has been developing projects to safeguard and enhance access to the cultural heritage of the HCRP. The medical library collection was identified early in the process as an important resource for learning about the evolution of health and care sciences from the late 19th through 20th centuries. After the collection was sanitized and organized, the library was relocated to a renovated room. Some periodicals and the main publications of the HCRP — including the journal *Rovisco Pais* and the patient newspaper *Luz* — have been scanned and made accessible through the Digital Library section of the library's webpage.

Collection materials from the HCRP's former medical library and laboratory total around 4,350 volumes and 740 titles, 51% of which are monographs and 49% of which are periodical publications, mainly scientific magazines and journals. The oldest work, *Ensaio Dermosographico ou Succinta e systematica descripção das Doenças Cutaneas* (1823), was written by Bernardino António Gomes, a

prominent physician who also authored the first modern census of Hansen's disease patients in Portugal.

About 40% of the collection's materials originated outside of Portugal and represent the work of leading authors, associations, and health organizations of the time, especially in the fields of dermatology and leprology. In some cases, the materials are rare and not available in any other collection in Portugal.

The restored collection opened officially under the name Hospital Colónia Rovisco Pais Scientific Library in a public ceremony held on March 20. Attendees included Takahiro Nanri, Executive Director of SHF; Suzana Menezes, Cultural Regional Director of the Portuguese Government; Helena Teodósio, Mayor of Cantanhede; and Isabel Bento, President of the Board of Directors of CMRRC-RP.

The Scientific Library contributes to the HCRP Museum's mission of preserving cultural heritage, and its opening in 2023 feels especially appropriate considering the 150th anniversary of the identification of the leprosy bacillus by Dr. Gerhard Hansen.



The Hospital Colónia Rovisco Pais Scientific Library, housing restored materials dating from 1823, opened on March 20, 2023.

**Further information about the Scientific Library
and how to access resources:**

<https://www.hansen-stories.pt/en/library/>



LETTER



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

Born and raised in a leprosy colony, and a person affected by leprosy herself, Maya Ranavare has been working for the empowerment, welfare, and rights of persons affected by leprosy and their families for over 20 years. She became APAL's president in July 2022.

<https://www.apalindia.in/>

Update from APAL's new president, Maya Ranavare

Since taking on the role of president of the Association of People Affected by Leprosy (APAL), I have visited many leprosy colonies in various states and met related government authorities in their offices. Being able to observe situations first-hand has been good for me and has facilitated my analysis of what is necessary. Many women of all ages came forward and explained their important requirements like never before, and I was pleased to note their high level of confidence and self-belief.

Extra effort needed to reach tribal populations

Regarding health care and social services, some areas require improvement. In particular, program implementation tends to be weak in difficult-to-reach and tribal areas. Control of leprosy in tribal populations requires extra effort. Accurate and timely detection of leprosy in these underprivileged communities is an important step toward achieving the goal of zero discrimination. Increased awareness among the tribal population about the signs and symptoms of the disease is important for achieving the target of a "leprosy-free India."

Lowering barriers to participation

At APAL, we face challenges that are shared by many people's organizations and persons affected by leprosy: illiteracy, low education, lack of digital skills, and inability to communicate in English. These factors make many persons affected by leprosy feel hesitant about participating in meetings, conferences, and workshops where standards for presentations are high and discussions proceed at a quick pace. For the world to understand the diversity of the leprosy community, our participation is necessary, but many of us need some accommodations for our participation to be meaningful.

I urge organizations, foundations, and trusts to imagine going for a walk with a friend. When you care about that friend and want to listen to them, you adjust your speed as necessary to continue walking side-by-side. You pay attention to your friend's stamina and choose a path for the day that both of you can complete. You notice the level of your friend's speech and try to match it. These are the kinds of accommodations that we need for participation in international events.

Awards and honors

Lately, executive members of APAL have been receiving recognition for their services to the leprosy community. Awards and honors are useful to persons affected by leprosy for overcoming self-stigma and developing an identity as champions and role models for the leprosy community. I want to encourage this trend toward public recognition, and so I will list some recent awards and honors here, starting boldly with my own:

- Ms. Maya Ranavare, President of APAL, received a Durga Ratna award for 21 years of tireless valuable service. Also, she was selected to speak as a representative of all people's organizations at the 21st International Leprosy Congress and the International Symposium at the Vatican on Hansen's Disease.
- Ms. Keroline Bhengra, Executive Member of APAL, was honored at a regional press conference in Champa.
- Mr. Ramavarai Sah, Joint-Secretary of APAL, was honored as a Special International Guest at the grand celebration of the 25th International Day of Dignity and Respect organized by IDEA Nepal.
- Mr. Prakash Done, Treasurer of APAL, was honored with a memento for being a best social worker in Andhra Pradesh for 12 years at an international BC Association celebration.

Thank you to the Sasakawa Health Foundation and other well-wishers for supporting and sustaining us always.



APAL's president, Maya Ranavare, at the ceremony where she received a Durga Ratna award. In India, awards that include the name "Durga" are given to women who have qualities similar to the goddess Durga, who is known as a brave fighter on behalf of those who need protection.

LETTER



Al Kadri
Chairman, PerMaTa Indonesia

Founded in 2007, PerMaTa aims to secure a decent quality of life for persons affected by leprosy in Indonesia through awareness-raising, empowerment, and advocacy. After serving as chairman of the organization's South Sulawesi branch, Al Kadri was elected chairman at the national level in 2022.

<https://www.facebook.com/permata.nasional>

New chairman of PerMaTa Indonesia shares his goals

I am very honored to have been elected by the people affected by leprosy in Indonesia to be the chairman of PerMaTa. PerMaTa is a national organization by and for persons affected by leprosy with several branches; however, currently only the branch in South Sulawesi, where I live, is very active and able to help persons affected by leprosy in its area. My new position is therefore a very big challenge for me, as it is my task to rebuild PerMaTa better than before.

In general, I hope for the future that actors at national and international levels pay more attention to the leprosy situation and to the people affected by it in Indonesia. Indonesia is number three in the world in terms of new cases of leprosy, and although the disease has officially been eliminated at the national level, in reality it is still a major problem for the public health system and especially for the affected people and their families. My big hope is that we can recruit many more partners and supporters for our cause, here in Indonesia and around the world, so that we can work together to eliminate leprosy and end stigma and discrimination against those affected. We must realize that even if the day comes when there are no new cases of leprosy, its terrible consequences will continue to haunt the hundreds of thousands who are already affected.

Our goal as PerMaTa is to help as many people as possible, old and young, throughout Indonesia. We want to strengthen the capacity of those affected, especially young people, so they can advocate for equitable and inclusive government programs and services. To do this, we want to expand our core program of identifying and supporting people affected by leprosy during and especially after treatment, motivating them, qualifying them and, where possible, helping them directly to overcome their problems.

This is a very big task for us. In general, the interest and attention for leprosy is much lower today than 10 years ago. There is very little understanding of leprosy among the population, where there are stigmatizing misunderstandings that are not easy to correct. There are also many challenges on the part of the people affected by leprosy themselves, many of whom do not feel able or courageous enough to fight together with us for better conditions. We need

to strengthen not only their self-confidence, but also our own professional management skills, which we lack to a considerable extent. In my home province of South Sulawesi, we are working with an external local non-governmental organization called YDTI, and we want to expand this type of partnership to other provinces and PerMaTa branches. It is important to do this slowly and very thoroughly in order to build the trust of partners and donors whose help we need in many ways.



Capacity-building event co-organized by PerMaTa and YDTI for young people on the theme of gender issues.

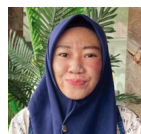


Young and old persons affected by leprosy engaged in a social mapping activity to identify ways that youth can take advocacy steps toward fulfilling the rights of the elderly.

PerMaTa South Sulawesi's young leaders confirm value of peer support

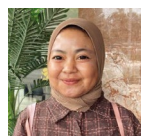
PerMaTa is a people's organization founded in Indonesia in February 2007. It operates in three provinces — East Java, South Sulawesi, and East Nusa Tenggara — and has 2,100 members nationwide. In early March, the Sasakawa Leprosy (Hansen's Disease) Initiative visited branches in four

districts of South Sulawesi — Bantaeng, Bulukumba, Gowa, and Jeneponto — and asked young members to share their aspirations as leaders. Their inspirational responses confirm the importance of opportunities to receive peer support and experience fellowship.



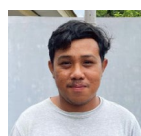
Eka (32)
Bantaeng

It is not easy to advocate at the health office sometimes, but supporting those in need gives me motivation!



Fira (19)
Bantaeng

I joined PerMaTa in 2022. Happy to support those who suffered like me.



Safwan (24)
Bantaeng

I'm so happy to have made so many friends from PerMaTa!



Ardi (38)
Bulukumba

Happy to contribute not only to Bulukumba but also to the whole of PerMaTa!



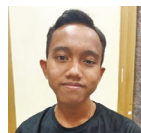
Sukma (25)
Bulukumba

Glad to know I'm not alone with the challenges I am facing due to leprosy.



Zul (23)
Bulukumba

I have more confidence in myself now!



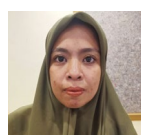
Apli (16)
Gowa

I'm so happy to have new friends!



Arfah (21)
Gowa

My dream is to be a leader who really supports persons affected by leprosy!



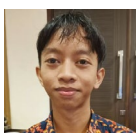
Dewi Sri (31)
Gowa

It's my great joy to see young persons affected by leprosy get better!



Ermawati (33)
Gowa

I want as many people as possible to know the correct knowledge about leprosy!



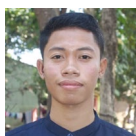
Firdaus (19)
Gowa

Glad I've made new friends! I want to widen this circle!



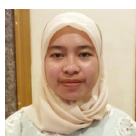
Iyank (19)
Gowa

Having good friends has made every day better!



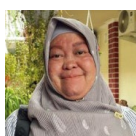
Rahmat (25)
Gowa

We are committed to spreading correct knowledge about leprosy in order to achieve an Indonesia free from stigma and discrimination.



Rahmawati (27)
Gowa

I want to support those who suffer!



Rahmawati (32)
Gowa

I want to support more young people affected by leprosy!



Ridho (21)
Gowa

The moments when young persons affected by leprosy open up to me gives me great joy!



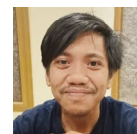
Roni (26)
Gowa

I found out that there are many young friends suffering more than I did. I want to help and support those in need!



Salmawati (40)
Gowa

I am responsible for a microfinance project. I want to support my fellows on the financial side!



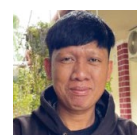
Zulfikar (25)
Gowa

To be a young man who helps others has been my wish since I was a little boy, and with PerMaTa that wish has come true. I am very grateful.



Eka (23)
Jeneponto

The reaction prevented me from going to school for a year. I now find fulfillment in supporting others who suffer as I once did.



Firman (32)
Jeneponto

Two years ago, I was locked in my room. Now I am happy every day. And I want to support those who suffer as I did.



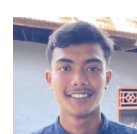
Kaharuddin (33)
Jeneponto

I will continue to visit those who suffer until they get better!



Kasmawati (27)
Jeneponto

Happy to have such good friends. PerMaTa is my family.



Rudi (20)
Jeneponto

I had an operation on my hand last year after a delay in treatment. Now I am well and I am working hard and enjoying my life with my friends.



Nirwana (23)
Takalar

I want to contribute more for persons affected by leprosy!



Yuliati (32)
Takalar

I'll do my best to support young persons affected by leprosy!

Event in Bergen marks 150th anniversary of Hansen's discovery of the leprosy bacillus

On Feb. 28, 2023, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa joined in marking the 150th anniversary of the discovery of the leprosy bacillus by Dr. Gerhard Armauer Hansen by attending an event at the University of Bergen in Norway.

Dr. Hansen was born in Bergen, and he discovered the leprosy bacillus on Feb. 28, 1873, in his Bergen laboratory. At the time, Bergen was the center of leprosy research worldwide, and for more than half a century, leprosy researchers from all over the world visited Bergen to study the disease. Dr. Hansen was one of the first to advocate for the establishment of a medical school in Bergen, and the University of Bergen, which opened in 1946, considers him one of its founders.

The commemorative event began solemnly with a choral performance by the Grieg Academy. In addition to the Goodwill Ambassador, speakers included Margareth Hagen, Rector of the University of Bergen; Linn Kristin Engø, Mayor of Bergen; Abbi Patrix, great-grandson of Dr. Hansen; and experts from the University and City of Bergen, who shared their views on the past, present, and future of the disease and related issues.

Mr. Patrix said that Dr. Hansen wrote in his journal when he was 69 years old that he was not confident in his memory or physical strength, and so would write things down before they were lost. Mr. Patrix himself happens to be 69 years old this year, but he still feels mentally sharp and physically strong. He attributes his health to the great strides taken by medical science, and he believes that pioneers like his great-grandfather changed the course of humanity.

The Goodwill Ambassador emphasized that despite a widespread impression that leprosy is a "disease of the past," it is in fact an "ongoing disease" with 200,000 new cases registered annually worldwide. It is also a disease that continues to be misunderstood. More than 100 discriminatory laws — including prohibitions against

using public transportation and recognition of leprosy as a legitimate reason for divorce — are wrongly still in force in over 20 countries. In order to achieve "zero leprosy," it is necessary to continue to send a message to the world that leprosy and related stigma and discrimination should not be neglected under any circumstances. In closing, the Goodwill Ambassador urged everyone to unite under the banner of his "Don't Forget Leprosy" campaign.

Recording of commemorative event:

<https://hansen2023.org/event/>



Recording of commemorative webcast:

<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/3456/>



Information about international conference in June:

<https://hansen2023.org/>



Placing a wreath at the place where Dr. Hansen's ashes are buried in the Botanical Garden outside the University of Bergen Museum. From left to right: Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination; Abbi Patrix, great-grandson of Dr. Hansen; Linn Kristin Engø, Mayor of Bergen; Margareth Hagen, President of the University of Bergen; and Magnus Vollset, Associate Professor at the University of Bergen and head of the 2023 Hansen Anniversary program committee.

