LEPROSY BULLETIN

NO. 117 OCTOBER 2023



"Don't Forget Leprosy" campaign shifting focus to national level

Message from the ambassador

Two years have passed since I launched the "Don't Forget Leprosy / Hansen's Disease" campaign. Initially, the campaign aimed to spread the message that efforts to eliminate leprosy and related stigma and discrimination must continue even during the pandemic. During this period when meeting in person was not possible, the campaign team at the Sasakawa Leprosy (Hansen's Disease) Initiative organized a webinar series and provided emergency support to organizations of persons affected by leprosy.

When possibilities for international travel started returning to pre-pandemic conditions, the Initiative organized three international conferences, which were held in Hyderabad (India); Rome (Italy) and Vatican City; and Bergen (Norway). With these conferences, we wanted to give stakeholders an opportunity to re-experience the value of inperson connection and increase momentum toward a world free of leprosy.

With global connections rekindled, the campaign has now moved on to supporting efforts at the national level. In September, I visited Bangladesh and met with Prime Minister Sheikh Hasina. Movement is underway to hold the country's second national leprosy conference in early November. In Brazil, a national conference has been scheduled for late November and President Lula has agreed to attend. Preparations are taking place for a national conference in Ethiopia sometime next year, and India is considering a national conference on elimination of leprosy-related discriminatory laws.

I will be 85 years old next January, but my commitment to the elimination of leprosy remains as strong as ever. I will continue to make every effort to realize a society where no one is left behind and everyone can participate.

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Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

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Dr. Paul Fine Professor of Communicable Disease Epidemiology London School of Hygiene & Tropical Medicine

Dr. Fine is an expert in communicable diseases and their transmission. For nearly 30 years, he directed a large epidemiological research program that investigated leprosy, tuberculosis, and HIV in the Karonga district of Malawi. His methods have emphasized family studies and vaccine evaluation.

"Interruption of transmission": A challenge

There has been much discussion of global targets for leprosy control ever since the initial declaration in 1991 to "eliminate" the disease "as a public health problem," defined as reduction of prevalence below 1 case per 10,000 population. The current (2021–2030) global leprosy strategy, entitled "Towards Zero Leprosy," states that WHO has "reset the target for leprosy elimination, defined as no new autochthonous cases as a result of interruption of transmission." On close inspection, it is not entirely clear what this means. Autochthonous cases are implicitly defined as "non-foreign" despite the fact that a foreigner may contract M. leprae infection in their new home and become an autochthonous but foreign-born case. And the phrase "interruption of transmission" is also problematic - as we have no good assay for *M. leprae* infection, we cannot directly measure what is to be interrupted! Instead we measure clinical disease, which is not itself transmitted; it only occurs in some individuals and even then only some years after infection.

Semantics aside, there are major questions to be addressed in association with these ambitious goals, in particular the effectiveness of different control approaches, be they a new vaccine, different modes of chemoprophylaxis, or different policies for case finding and treatment. We have long recognized that leprosy is associated with poverty but have little idea what feature of improved living standards is inimical to the infection. Does infection transmission not occur in better economic conditions, as in contemporary Europe, despite the presence of considerable numbers of apparently infectious immigrant cases? Or do some individuals become infected but not develop clinical disease under such conditions? In order to study this we need an assay which can recognize paucibacillary infections with M. leprae, a challenge which has stymied researchers for many years. Recent advances in immunology might provide a solution to this but few scientists are working on the problem.

The role of the armadillo in the Americas emerges as a major – and embarrassingly neglected – question. Zoonotic leprosy

has been confirmed repeatedly in the United States, but its contribution to leprosy in Latin America remains totally unknown. It is now possible to address this issue rigorously by sequencing *M. leprae* in armadillos and in human cases. The presence of this reservoir indicates that zero leprosy is not a feasible global goal. Should this not be acknowledged?¹

There is an implication of finality in much of the target language — in the words *elimination*, *interruption*, and *zero* leprosy. This implication may be considered useful as an advocacy tool, but the optimistic prediction of no more leprosy may discourage some young scientists from taking up leprosy as a career and contribute to the loss in expertise needed at this stage in the global effort against the disease. Perhaps it might be better to have a simpler and more conservative target: for example, just to continually reduce the actual incidence of clinical leprosy and the number of disabled patients in every endemic population. (The word actual in this sentence is crucial for emphasizing the need to maintain surveillance as some of the recent apparent declines in disease are attributable to reduced attention and failure to recognize or report cases.) Leprosy organizations would do well to consider the long term implications of this endeavor – how to preserve leprosy expertise, which will be needed far into the future, indefinitely at least in the Americas, and how to transition leprosy programs and resources as the disease declines to very low levels to address other related public health problems.

Editor's note: Dr. Fine gave a 30-minute keynote speech on this topic at The Bergen International Conference on Hansen's Disease held in Norway June 21–22, 2023, during which he used slides to share data and explain his thoughts in further detail. A video recording of his speech can be accessed at the link below.

Recording of Dr. Fine's keynote speech in Bergen https://bit.ly/3PP0UhX



¹ To read more about armadillos as a large natural reservoir of *M. leprae*, start with Gayathriy Balamayooran, Maria Pena, Rahul Sharma, Richard W Truman, "The armadillo as an animal model and reservoir host for *Mycobacterium leprae*," *Clinics in Dermatology* 33, no. 1 (2015): 108–115, https://doi.org/10.1016/j.clindermatol.2014.07.001.



Dr. Venkata Ranganadha Rao Pemmaraju **Program Advisor for Medical Issues** Sasakawa Leprosy (Hansen's Disease) Initiative

Dr. Pemmaraju has decades of experience in all aspects of leprosy control. His technical and administrative knowledge is balanced by time spent with persons affected by the disease. His previous positions include Acting Team Leader of the WHO Global Leprosy Programme.

Observations regarding WHO's Global Leprosy (Hansen disease) update based on 2022 data

Editor's note: Since 2019, WHO has added Hansen disease (not Hansen's) to the title of its annual global update. The WHO Style Guide (2004) recommends as follows: "Eponymous names give no information about the nature of a disease or syndrome, and different names may be used in different countries. They should be avoided whenever possible; where eponymous names must be used, the apostrophe "s" is unnecessary."1

"Global Leprosy (Hansen disease) update, 2022: new paradigm – control to elimination"² presented reports received from 182 out of 221 (80%) countries and territories using DHIS2 software, an open source health information management system coordinated by the HISP Centre at the University of Oslo. This is an impressive achievement that fulfills WHO's function of monitoring the leprosy situation and publishing the leprosy (Hansen disease) update.

Globally 174,087 new cases were reported, which is an increase by 21.8% compared to new case detection during the COVID-19 pandemic. This increase is thanks to the committed efforts of national program health staff and all partners in continuing case detection. The "Don't Forget Leprosy" campaign promoted by Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, also contributed to sustaining commitment to the leprosy program. The 10-year trend from 2013 to 2022 showed a general decline in the number of new cases detected globally by 19.2% from 215,673 to 174,087 and this needs to be sustained through the last mile towards elimination of leprosy. A greater decline was observed in the number of new child cases by 48% from 19,799 to 10,302. A decline of new cases with grade 2 disabilities (G2D) by 28% from 13,305 to 9,554 was reported during the same period.

Uneven distribution of leprosy endemicity was obvious. The WHO South-East Asia Region accounted for 72% of new leprosy cases. Analysis of distribution at country level showed that 95% of new cases are reported from 23 global priority countries. The prioritization using a composite index was done in 2015 and countries were listed as global priority countries in 2015. Some countries need more analysis and perhaps attention; for example, Uganda reported 581 new cases in 2022 compared to 389 in 2021, 234 in 2020, and 219 in 2019. Similarly other countries like Chad (447), Central African Republic (402), and Papua New Guinea (495) have been reporting more cases than some of the global priority countries. A review of the composite index and applying it to all countries might be a useful exercise.

The number of new child cases indirectly reflects continued transmission of infection. In 2022, the total number of new child cases reported was 10,302. Eight countries reported more than 100 new child cases: India (5,586), Indonesia (1,226), Brazil (836), Ethiopia (364), Democratic Republic of Congo (328), Mozambique (221), Nigeria (155), and Papua New Guinea (133). Concern was expressed very rightly at detection of 278 new child cases with G2D. Of the 278 new child cases with G2D, 133 were from the African Region, which calls for improved case detection in this region.

The update also highlighted 108 laws that allow discrimination on the basis of leprosy and 13 instances of discrimination. Commitment is needed to reduce the number of these laws to zero.

Coverage of post-exposure prophylaxis, such as coverage of contact examination cohorts and implementation of single dose rifampicin, needs to be considered in the global leprosy update. Reporting on treatment completion rates needs to be promoted.

The subtitle "new paradigm – control to elimination" suits the article well considering that 54 countries have reported zero cases in 2023 and 17 (30%) have been reporting zero child cases for the past five consecutive years. These countries qualify for in-depth investigation and further verification for interruption of transmission.

¹ WHO Style Guide (2004), p. 30, https://eucliduniversity.net/wp-content/uploads/2015/12/who_style-

² WHO Weekly Epidemiological Record, 15 September 2023, WER No. 37, 2023, 98, 409-430, https:// www.who.int/publications/i/item/who-wer9937-409-430

LETTER



Dr. Alice Cruz Program Advisor for Human Rights Issues Sasakawa Leprosy (Hansen's Disease) Initiative

Dr. Cruz held the mandate for United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members from when it was first established by the Human Rights Council in 2017 until the end of her second three-year appointment in July 2023.

Open letter to the next Special Rapporteur: Acknowledge the true owners of your mandate

Being appointed as a United Nations Special Rapporteur is not only a great honor, but also evidence of the appointee's willingness to serve on a voluntary basis those who experience injustice. Therefore, my first words to my successor go to congratulate them for having made the selfless decision to put their time at the service of the global agenda of human rights. Human rights are the ethics that bind peoples and nations from different backgrounds in a common desire to build a free and fair world. Despite criticism against human rights for supposedly having a specifically Western origin, human rights are based on a widely shared and deeply human sense that all people are born equal and that all people should enjoy peace, security, and dignity on equal terms. In a world ravaged by conflict, inequalities, and climate change, we need human rights more than ever.

However, too many people are being pushed behind. That is one of the reasons why implementing the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members is a heavy responsibility in addition to being a deep honor. This mandate touches violations of nearly all civil, political, economic, social, and cultural rights. It also touches multiple intersections between discrimination against women, children, and older people and discrimination based on disability, race, and other grounds. And yet, this is a mandate that, in practice, struggles with limited support both from Member States and the administration of the human rights system. I have said many times that there was an active attempt to erase Hansen's disease from history. In fact, forced segregation fits Article 7 of the Rome Statute of the International Criminal Court and might be interpreted as a crime against humanity (however controversial that may be). Nowadays, we live with the consequences of such active invisibilization of Hansen's disease and the silencing of persons affected by it.

That is why, together with heartfelt congratulations to my successor, I send them my unshakable solidarity. One lesson I learned as the mandate holder is that there is a tendency

to forget to care about the carer. Women from all over the world know this too well. So my first wish is that my successor can find a way to practice self-care while delivering the mandate and that they can build a network of caring people around them. And I know that this is possible. If they have the humility to understand that their role is only to bridge persons affected by Hansen's disease with decision-makers and that the knowledge of persons affected is more important than any academic knowledge, my successor will discover how love is the only force capable of removing barriers. Persons affected by Hansen's disease, if put at the center, will not only inspire and guide my successor, but also care for them.

It may be that Hansen's disease was erased from history; it may be that the global human rights agenda tends to makes visible those issues that affect people with more bargaining power; it may be that due to systemic discrimination persons affected by Hansen's disease don't have access to opportunities and live in vulnerable situations; and it may be that they experience discrimination both in law and in practice. But the fundamental truth is that persons affected by Hansen's disease have been raising their voices for decades; they are organized and lead change in their national and sub-national territories; they know what works for eliminating discrimination better than anyone; and they know the value of dignity like no one else. Aside from any advice regarding how to make international human rights law embodied on the lives of persons affected by Hansen's disease (which my reports are full of), the best advice I can give my successor is this: be humble; be grateful; and reach out to those you committed to serve — not as beneficiaries of your work — but as the true owners of your mandate. The role of Special Rapporteur is ephemeral. The love you will receive, if you acknowledge the true owners of your mandate, is everlasting.

Editor's note: On October 13, the United Nations announced that the new Special Rapporteur will be Dr. Beatriz Miranda Galarza of Ecuador. Dr. Cruz wrote this letter before the announcement.

NEXT GENERATION



Diana Patricia Medina Córdoba Vice President Asociación de Pacientes de Hansen en Bolívar (Asohanbol)

Colombia is divided territorially into a capital district and 32 departments. Nine of these departments have associations of persons affected by leprosy (Hansen's disease). The associations coordinate their activities through the National Federation of Associations of Persons Affected by Hansen's Disease in Colombia (Felehansen).

Finding an extended family in Felehansen

My name is Diana Patricia Medina Córdoba. I was born in Cartagena, a port city in Colombia that faces the Caribbean Sea. When I was 10 years old, I was diagnosed with Hansen's disease. I am one of four people in my family to have had the disease. My father was diagnosed first, and then when a health team visited our home and checked the rest of our family, my sister, my uncle, and I were diagnosed as well.

Dr. Martha Cecilia Barbosa Ladino of DAHW German Leprosy and TB Relief Association (GLRA) guided me through each step of my journey with Hansen's disease — from diagnosis, through treatment, and its aftermath. She helped me and those around me to accept my diagnosis with greater understanding.

My city is the capital of a department called Bolívar. Over time, I discovered that there are many other people in Bolívar who have experienced Hansen's disease, and together they formed the Asociación de Pacientes de Hansen en Bolívar (Asohanbol). Members of the association welcomed me, and as I got more involved, I learned more about the disease. I understood clearly that it has a cure and that timely treatment can prevent disabilities.

2022/12/15 09:50

Members of Asohanbol gather for the distribution of kits containing goggles, a thermos, gloves, and oils for skin lubrication (Cartagena, Colombia, Dec. 15, 2022).

Now, at age 31, I am an active member of Asohanbol. As vice president, I belong to the board of directors, and I participate

in the public health support group for the district of Cartagena. For seven years, I have also been an educational agent for health, which involves sharing knowledge of Hansen's disease to eliminate discrimination and stigma. My colleagues and I use our own life stories to promote awareness, disability prevention, and inclusion throughout society. We talk to people in rural and urban areas, the national army, the police, health professionals, and schools. We believe firmly that a fairer world free of discrimination can only be achieved by working together.

Asohanbol is not alone in its efforts. We are one of nine associations that coordinate activities under an umbrella organization called Federación Nacional de Asociaciones de Personas Afectadas por Hansen en Colombia (Felehansen). Felehansen was founded in 2014 to give the associations and persons affected by Hansen's disease a greater presence at the national level. Each member association represents a department in Colombia with a relatively large number of cases.

Working together through Felehansen has made us into more knowledgeable leaders for our regions. Felehansen also helps us to strengthen our associations through coordinated workshops and projects, advocate at the national level for comprehensive care, and represent our associations at significant national and international events.

I thank God for the opportunity to connect with Asohanbol and join with fellow Felehansen members to find people who have been forgotten and give them a voice. Together we can be part of the solution, building a just world where Hansen's disease is not a reason for mistreating people, banishing them, or justifying violence or discrimination of any kind, because in the eyes of God, we are all equal.

I also thank Felehansen's president, Lucrecia Vásquez, for her dedication and patience and the Sasakawa Leprosy (Hansen's Disease) Initiative for believing in us and recognizing the strength of persons affected by the disease to overcome obstacles related to it. Thank you all for allowing me to be part of this big family. Each one of you will always be in my heart.

REPORT



Jiptha Boiragee Program Support Coordinator The Leprosy Mission Bangladesh

The Leprosy Mission (TLM) began direct operation in Bangladesh in 1991, and as of 2023, it is the largest organization working on leprosy in the country. TLM Bangladesh is the largest contributor to the National Leprosy Elimination Program of the Ministry of Health and Family Welfare.

Update from Bangladesh

In 2019, the National Leprosy Conference in Bangladesh was organized with the support of the Sasakawa Health Foundation and graced by the Honorable Prime Minister Sheikh Hasina. At this historic event, the Prime Minister openly shared her personal connection to leprosy and her determined vision to achieve "zero leprosy by 2030." However, the COVID-19 pandemic disrupted post-conference momentum toward the goal, and the number of new cases detected dropped by nearly 900 between 2020 (3,766) and 2021 (2,872).

Reviewing the 2022 annual report of the National Leprosy Programme (NLP), we note evidence that detection efforts are recovering: 2,988 new cases, with 6.22% G2D (grade 2 disability) and 4.93% child cases. Bangladesh's average number of annual new cases, G2D, and child cases has remained consistent since 1999.

Despite these achievements, it must be said that overall detection efforts have declined since Bangladesh reached the elimination target in 1998. The government and nongovernment sector reduced support, particularly in terms of funding for new case detection initiatives. The funding shortfall has also had a ripple effect on capacity building, patient follow-up during and after multidrug therapy (MDT) treatment, and engagement in leprosy-related activities at the district and upazila (sub-district) levels. Such limitations have compromised active case finding, a vital leprosy transmission interruption strategy. The government's upazila-based budget allocation determines how much support can be provided by local health staff, TB Leprosy Control Assistants, and Program Officers.

MDT treatment courses are 6 months for paucibacillary and 12 months for multibacillary. The blister packs of MDT drugs are provided by the government's Upazila Health Complex, but persons affected by leprosy have mentioned that time constraints, travel burdens, and daily income loss, coupled with economic vulnerabilities, make it a daunting task to collect them. A feasible solution would be to distribute MDT through Community Clinics, offering convenience for patients and facilitating easier referral of any complications. Furthermore, Community Health Care Providers could seize the opportunity to screen the family members of index cases

during MDT distribution and follow-up, reducing default rates, decreasing stigma, and enhancing timely complication identification and referrals.

From 1985 to 2022, NLP data highlights over 28,748 individuals disabled by leprosy, indicating demand for hospital-based complication care. Currently, only three government leprosy hospitals serve in three districts, limiting access for non-local patients. Utilizing existing medical college facilities nationwide for leprosy-related complication care could enhance accessibility and care quality. Meanwhile, funding for NGO-managed leprosy hospitals faces a critical situation.

Single dose rifampicin (SDR) is a proven chemotherapy for preventing leprosy transmission among contacts. In its Global Leprosy Strategy 2021–2030, WHO called for scaling up preventive chemotherapy. Bangladesh's National Strategic Plan for Leprosy 2023-2030 aligns with this strategy, but implementation requires significant funding and capacity building.

Bangladesh has no discriminatory laws against persons affected by leprosy and their family members. However, inclusivity in areas like social, economic, educational, and employment opportunities remains a challenge. To address this, leprosy experts recommend widespread leprosy education, integration into healthcare, community counseling, and active anti-discrimination laws. Leprosy organizations in Bangladesh can contribute by promoting education, referrals, and safety net services. They can work as mediators and influence authorities to secure the human rights of persons affected by leprosy and their family members.



Community Health Care Provider (CHCP) conducts leprosy education for individuals seeking health services at a community clinic in southwestern Bangladesh (2022).

Goodwill Ambassador visits Bangladesh for the first time in four years

Sept. 3-5, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Bangladesh for the first time since he attended the First National Leprosy Conference held nearly four years ago in December 2019.

During his visit, he met with Prime Minister Sheikh Hasina, Foreign Secretary Masud Bin Momen, Minister of Health and Family Welfare Zahid Maleque, Secretary of the Health Service Division Anowar Hossain Howlader, and WHO Representative to Bangladesh Bardan Jung Rana. He appealed to the leaders to hold a second national conference on leprosy within 2023.

Bangladesh's First National Leprosy Conference was supported by The Nippon Foundation and Sasakawa Health Foundation. At the conference, Prime Minister Sheikh Hasina declared that Bangladesh would reach zero leprosy by 2030. Her declaration, coming from the nation's top leader. encouraged everyone in the country to work toward the goal.

At around the same time as the conference, a novel coronavirus started spreading around the world, and by 2020 the COVID-19 pandemic was affecting healthcare and disrupting leprosy control efforts worldwide. Now that the pandemic has subsided, the time is right for a second national conference to revive momentum toward the goal.

Over the next few months, I will be in close contact with the Prime Minister's Office, the Ministry of Foreign Affairs, and the Ministry of Health and Family Welfare to encourage followthrough on holding a second national conference before the end of the year.



Sept. 4 – World Health Organization (WHO) Bangladesh – Goodwill Ambassador Sasakawa and WHO Representative to Bangladesh Bardan Jung Rana hold a "Don't Forget Leprosy" campaign banner after discussing the possibility of a second national conference. Dr. Bardan encouraged the proposal, expressing his hope for an interactive conference that leads to concrete actions.



Sept. 5 – Prime Minister's Office – Goodwill Ambassador Sasakawa and Prime Minister Sheikh Hasina discuss the possibility of a second national conference in Bangladesh. The Prime Minister spoke about her concern for persons affected by leprosy and the actions she was taking even before assuming her current position.



Sept. 4 – Ministry of Health & Family Welfare – (from left) Ambassador of Japan to Bangladesh Kiminori Iwama, Secretary of the Health Services Division Anowar Hossain Howlader, Minister of Health and Family Welfare Zahid Malegue, Goodwill Ambassador Sasakawa, Director General of Health Services Abul Bashar Mohammad Khurshid Alam, and Additional Secretary of the Health Services Division Md Saidur Rahman stand with a "Don't Forget Leprosy" campaign banner. The Ministry agreed to support a second national conference.

Report on the First Bangladesh National Conference in 2019

https://bit.ly/3LPR2mN

Details of meeting with Prime Minister Sheikh Hasina on Sept. 5, 2023 https://bit.ly/3rHD2Vj





ANNOUNCEMENT

Armauer Hansen International Film Festival to be held in Bergen in October



The world's first film festival on the topic of leprosy (Hansen's disease) will be held in Bergen, Norway, from October 24 to 26, 2023. Co-sponsored by the Bergen International Film Festival and the Sasakawa Leprosy (Hansen's Disease) Initiative, the festival is part of a

series of events organized to commemorate the 150th anniversary of Dr. Armauer Hansen's discovery of the leprosy bacillus. The organizers hope that the festival will provide an opportunity for many people to learn about leprosy and think about actions that they can take.

Films featured at the festival

The Last Mile

Naohiro Asano · 2017 · Japan · 103 minutes

This documentary follows Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination and Chairman of The Nippon Foundation, as he tackles the issue of leprosy over the course of half a century. Goodwill Ambassador Sasakawa is scheduled to address the audience on October 24, the opening day of the festival.

The Motorcycle Diaries

Walter Salles · 2004 · multiple countries · 127 minutes

This biographical film follows Ernesto "Che" Guevara as he is transformed by a journey across the South American continent with his friend, Alberto Granado, in 1952. At the San Pablo leprosarium in the Peruvian jungle, future revolutionary Guevara gives his first political speech.

Sweet Bean

Naomi Kawase · 2015 · Japan · 113 minutes

Based on a novel by Durian Sukegawa that has been translated and published in 13 countries, this film features a former leprosy patient who confronts prejudice as she works at a shop making dorayaki, a snack made of castella pancakes and sweet bean paste filling.

Yomeddine

A.B. Shawky · 2018 · Egypt · 97 minutes

This comic drama follows a man cured of leprosy who decides to leave the colony where he was raised and search for the family that abandoned him. The main role is played by Rady Gamal, a person affected by leprosy who, like the character, grew up in a leprosy colony.

Bergen International Film Festival website https://bit.ly/46mpf5t





WHO Goodwill Ambassador's Leprosy Bulletin No.117

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



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