WHO GOODWILL AMBASSADOR'S

LEPROSY BULLETIN

NO. 115 JUNE 2023

Leaders uniting in pursuit of a leprosy-free world

Message from the ambassador

May 22–26, I attended the 76th World Health Assembly in Geneva, Switzerland. Last year, some of the annual gathering's activities were still online, but this year I did not notice any impact from the COVID-19 pandemic.

As in past years, I kept a busy schedule with a focus on countries where leprosy is endemic. I met with health ministers from 17 countries (Angola, Bangladesh, Brazil, Comoros, Cote d'Ivoire, Egypt, Ethiopia, India, Indonesia, Kiribati, Madagascar, the Marshall Islands, Nepal, Norway, Pakistan, South Sudan, and Sri Lanka). In addition to urging them to tackle leprosy and related issues, I asked for their cooperation with the "Don't Forget Leprosy" campaign.

I also met with Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, and Mr. Volker Türk, United Nations High Commissioner for Human Rights. I told the High Commissioner that, according to my estimate, tens of millions of persons affected by leprosy and their family members are still suffering from discrimination, and I asked for his help in changing the situation.

Through discussion with representatives from various countries, I learned that leprosy elimination activities that had stalled because of the pandemic are showing signs of resumption. I received requests for visits from many countries, including Brazil, where there is a new government, and Pakistan, where I have never visited. I believe that "answers are to be found where the problems are," and so I feel grateful for these requests. I am eager to do all that I can to accelerate the pace towards a leprosy-free world.

笹川陽平

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Ethel Noia Maciel
Ministry of Health (Brazil)
Dr. Alda Maria da Cruz
Ministry of Health (Brazil)

Dr. Sandra Maria Barbosa Durães
Ministry of Health (Brazil)
Dr. Suzan Trienekens
Leprosy Research Initiative

Dr. David Pahan
Lepra Bangladesh
Nikita Sarah
The Leprosy Mission Trust India

Subhojit Goswami
The Leprosy Mission Trust India
Mohan Arikonda
APAL (India)

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

VIEWPOINT

Dr. Ethel Noia Maciel, Secretary

Health and Environment Surveillance Secretariat (SVSA)

Ministry of Health, Brazil

Dr. Alda Maria da Cruz, Director

Dept. of Transmissible Diseases (DEDT)

Health and Environment Surveillance Secretariat (SVSA)

Ministry of Health, Brazil

Dr. Sandra Maria Barbosa Durães

General Coordination for Surveillance of Diseases in Elimination (CGDE)

Health and Environment Surveillance Secretariat (SVSA)

Ministry of Health, Brazil

Brazil's commitment to realizing a world without Hansen's disease

The worldwide implementation of multidrug therapy (MDT) according to World Health Organization (WHO) guidelines in the 1980s dramatically decreased the prevalence of Hansen's disease (HD). However, over the past decade, the detection rate of new cases worldwide has remained almost unchanged, with Brazil, India, and Indonesia contributing the most number of these new cases.[1]

Recent reports from India suggest a rise in newly detected cases.[2] In Uganda, although detection rates are constantly decreasing, there are still geographic pockets of disease persistence,[3] and in Chad, there is an evident delay in diagnosis and management of HD cases.[4] Brazil, in the last two decades, has seen a slow and steady downward trend in New Case Detection Rates (NCDR). Because this downward trend has happened together with an increase in the mean age of new cases and a decrease in annual children NCDRs, we can assume that transmission is actually decreasing. Although the number of new cases detected annually is still very high, with late detection and many hidden cases, epidemiologically the decrease is conspicuous.

The continuing efforts carried out by Brazil's Ministry of Health focusing on the decentralization of healthcare made it possible to achieve a reduction in the HD detection rate. Between 2010 and 2019, the national detection rate decreased by 37.7%, from 18.22 per 100,000 inhabitants in 2010 to 13.23 per 100,000 inhabitants in 2019.[5] However, a study of the NCDR from 2006 to 2017 found that Brazil was still registering a high number of cases affecting children or with physical disabilities, suggesting an urgent need to strengthen early diagnosis and treatment.[6]

More recently, the public health emergency caused by the COVID-19 pandemic had a significant impact on HD case detection, with a decrease in the number of new cases from 27,864 in 2019 to 17,979 in 2020, which represents a 35.8% decrease in the overall detection rate within just one year.[5]

Despite the challenges, there were also important advances, such as the elaboration of the National Clinical Protocol and Therapeutic Guidelines for HD (PCDT), which defines diagnostic criteria, pharmacological and non-pharmacological treatments, a psychosocial approach for stigma and discrimination, guidelines for contact tracing, follow-up and monitoring of patients, as well as the management and control mechanisms within the scope of Brazil's Unified Health System (SUS).[7]

We would also like to highlight the incorporation of two new diagnostic supporting tests. One of them is a point-of-care serologic test that identifies IgM against anti-*Mycobacterium leprae* (Ml Flow)[8] for use in primary health care (PHC) as a screening tool for contacts with initial and discrete MB types of the disease and for healthy contacts with higher risk to develop HD in the future. The second new test is a qualitative molecular detection test that is useful for suspected cases of paucibacillary forms to be used in specialized assistance.[9]

Brazil's Ministry of Health provides minocycline and ofloxacin as second-line drugs for drug resistance and for adverse effects of MDT, and recently, clarithromycin was also incorporated for cases of rifampicin resistance. All these drugs are distributed free of charge to patients. Additionally, in compliance with international guidelines for monitoring the threat of antimicrobial resistance, an automated and quicker genotype test for the diagnosis of drug resistance was developed and adopted for reference laboratories at state and municipal levels.

The WHO Global Leprosy Strategy 2021–2030 focuses on interrupting transmission and achieving zero autochthonous cases. It aims to motivate professionals in high-burden countries to accelerate activities while compelling low-burden countries to complete the unfinished task of making HD a disease of the past.[10]

In Brazil's new government, General Coordination for Surveillance of Diseases in Elimination (Coordenação-Geral de Vigilância das Doenças em Eliminação, CGDE) within the Health and Environment Surveillance Secretariat (Secretaria de Vigilância em Saúde e Ambiente, SVSA) is responsible for Brazil's National HD Program. To achieve the challenging goals set by WHO, Brazil's National HD Program will support training projects aimed at primary health care professionals in partnership with federal universities (UFBA, UFMT, UFPI, UFRN, UFC, UFG and UFMA), national and international foundations (Fiocruz, Sasakawa Health Foundation, and Novartis Foundation), and medical societies (Brazilian Society of Dermatology). In 2023, these projects will cover municipalities in 19 states.

For the Ministry of Health, the HD program is a priority, and a large contribution of resources will also allow the development of projects, such as new diagnostic methods; studies on the LepVax vaccine; and studies to evaluate the viability of *M. leprae* by molecular analysis, during and after multidrug therapy. We also aim to develop the national production of MDT drugs; conduct a National Survey of Post-Treatment Physical Disability and a National Survey to Estimate the Occurrence of Stigma and Discrimination; as well as create a Brazil Network for Information Management and Knowledge.

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From left, Dr. Sandra Maria Barbosa Durães, Dr. Ethel Noia Maciel, and Dr. Alda Maria da Cruz are the new team in Brazil's Ministry of Health leading Brazil's National Hansen's Disease Program. They are committed to realizing a world without Hansen's disease.

ANNOUNCEMENT

Dr. Suzan Trienekens
Coordinator, Leprosy Research Initiative (LRI)

Dr. Trienekens joined LRI in May 2022 after completing her Ph.D. project on schistosomiasis transmission in children. Her experience includes over ten years of working as a field epidemiologist and public health researcher in Europe and Africa. She also supports the Global Partnership for Zero Leprosy in implementation of their research agenda.

https://leprosyresearch.org

Leprosy Research Initiative reaches 10-year milestone

The Leprosy Research Initiative (LRI) was set up in 2013 to boost research in leprosy after years of declining funding opportunities and a scattered funding landscape. It is a unique collaborative venture among partners who pool funding to support research projects across shared priorities. Guided by a Steering Committee, an independent Scientific Review Committee, an Executives Group, and the Secretariat, LRI works towards the three zeros of leprosy elimination by supporting research and researchers as well as translating findings into policy and practice.

LRI funds projects on five priorities in applied leprosy research, set jointly by stakeholders such as researchers, persons affected by leprosy, health professionals, and policy makers. In every annual call, LRI welcomes proposals on transmission, diagnostics, operational research, disability, and stigma and discrimination. In addition, research proposals on specific focus areas are invited when further need is identified. A robust review process including several steps and reviewers as well as monitoring of running projects ensures high scientific quality.

LRI brings committed people together. Partners have joined forces to reach their shared goal of zero leprosy. Projects are often collaborations among several researchers across institutes, countries, and even continents. During the annual LRI Spring Meeting, researchers from ongoing LRI-funded projects presented their progress and findings to partners, committees, and each other. The Meeting provides a much-valued platform for making new connections, fostering collaborations, and stimulating shared learning. Over the past 10 years, many new researchers have submitted grant applications and several new partners have joined LRI.

With the structural funding available, LRI has contributed funding to over 80 research projects in more than 20 countries to date. LRI has encouraged and supported researchers from leprosy-endemic countries, reflected in stronger representation in current projects. Reviewers notice that the quality of applications has considerably increased over time and there is more emphasis on meaningful involvement of persons affected by leprosy. It has also been inspiring to see that many early career researchers are motivated to contribute to impactful projects. To provide a further opportunity for them to improve research skills and gain experience, LRI recently launched a research capacity strengthening grant and received a large interest.

Looking towards the future, the LRI team hopes that the collaborative venture continues to be a resource for those who are committed to making a positive impact on leprosy control through research. We are aiming to maximize impact from supported projects and to strengthen partners' collaborations towards the goal of zero leprosy.

If you would like to learn more about LRI's work, apply for funding, or join LRI as a partner, visit our website (https://leprosyresearch.org) or contact us by email (info@leprosyresearch.org). We look forward to hearing from you!

Survey data collection for the project "Impact of SDR-PEP under routine programme conditions in Nepal" (NLR Nepal).

Attendees of the annual Leprosy Research Initiative (LRI) Spring Meeting (Breukelen, the Netherlands, April 2023).

REPORT

Dr. David Pahan
Country Director, Lepra Bangladesh

Lepra Bangladesh has been working for persons affected by leprosy and prevention of disability in Bogura District, Bangladesh, since 2000, mainly through community awareness raising, early case detection, and fostering self-care practice and the formation of Self-Help Groups (SHGs). These SHGs united at the district level in 2014, and in 2017, the Bogura Federation received its formal registration as a Community Based Organisation (CBO).

Bogura Federation's mental health initiatives

Bogura District Leprosy and Disability Development Association, also known as the Bogura Federation, was established in February 2014. The Federation is registered as a Community-Based Organisation (CBO) under the Government Social Welfare Department. It unites Bogura District's 101 Self-Help Groups (SHGs) and 12 Sub-District Federations for persons affected by leprosy, so that they can raise a common voice regarding their rights and entitlements. The Federation currently has 1030 members (474 male, 556 female), and it is also providing technical support to three other District Federations (Sirajganj, Pabna, and Natore) consisting of 300 SHGs with 3856 members.

Aiming for institutionalization of services

Leprosy (Hansen's disease) frequently causes distress and anxiety in affected persons and their family members because of both direct impact on wellbeing and the stigma and prejudice associated with the disease. According to an advocacy brief prepared by the Control of Neglected Tropical Diseases (NDTs) team of the World Health Organization, one in two people with leprosy or lymphatic filariasis experiences depression and/or anxiety.[1] Thus, mental health conditions and NTDs are highly interdependent and often occur together.

Bogura Federation has valuable experience implementing mental health projects (Mental Motivator) in its working areas in 2018 to improve mental wellbeing among persons affected by leprosy and their family members. This year, The Federation has been implementing a project called "Mind to Heart," supported by a grant from the Sasakawa Health Foundation, with the aim to institutionalize mental health initiatives for the greater interest of persons affected by leprosy and their family members. Institutionalization will increase accessibility and improve mental health care through establishing good referral linkage with other professional organizations and government institutes.

Mind to Heart (M2H) started in February 2023 with three project staff and 12 volunteers called Mental Motivators. Since then, project staff have organized a project orientation workshop, a project monitoring meeting, and a meeting with Federation leaders. Project staff and all Mental Motivators have also received special counseling training from Professor Shaheen Islam from the Department of Educational & Counseling Psychology of Dhaka University.

As part of the M2H project, 1200 people will receive awareness training on mental health issues; 800 persons affected by leprosy will benefit directly; and 150 persons with severe anxiety/depression will receive structured counseling by a professional counselor. A total of 30 persons (minimum expected) with severe anxiety/depression who require more specialized mental health support will be referred to a specialized institute. Bogura Federation leaders will also attend meetings at the national level for advocacy and networking with government officials and other important stakeholders.

Professor Shaheen Islam, Department of Educational & Counseling Psychology, University of Dhaka, facilitating mental health and counseling training for Mind to Heart (M2H) Mental Motivators and project staff (Bogura, Bangladesh, April 2023).

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[1] *Mental health of people with neglected tropical diseases: towards a person-centred approach. Geneva*: World Health Organization (2020): 4, https://www.who.int/publications/i/item/9789240004528.

REPORT

Nikita Sarah
Head
Advocacy & Communications
The Leprosy Mission Trust India

Subhojit Goswami
Senior Program Manager
Advocacy & Communications
The Leprosy Mission Trust India

The Leprosy Mission Trust India

The Leprosy Mission Trust India (TLMTI) is the largest leprosy-focused non-governmental organization in India. TLMTI upholds a philosophy of partnership for joint action and leverages its large network to implement programs in healthcare, sustainable livelihood, community empowerment, advocacy, and research and training.

https://www.leprosymission.in/

Efforts in India towards repealing discriminatory laws against leprosy

For millennia, leprosy evoked a sense of fear among people, especially due to ignorance. This fear fueled exclusion and discrimination against people affected by the disease, creating barriers to their participation as equal members of society and violating their rights. In addition to social attitudes, legal provisions also encouraged discrimination against persons affected by leprosy, and they continue to do so. Several acts and statutes in India, which were mostly formulated in the late 19th and early 20th century, allowed leprosy to be a ground for divorce and provided for the detention of persons affected by leprosy for an unspecified duration as the disease was then considered “incurable and virulent.”

Other legal provisions have prohibited persons affected by leprosy from accessing schools and colleges, gaining employment, and participating in local governance. While the need to amend and repeal such archaic laws was evident, the issue received prominence only in 2014 when the Union Ministry of Law and Justice announced its decision to remove all obsolete laws. Seeing an opportunity, The Leprosy Mission Trust India (TLMTI) and its partners created awareness and galvanized efforts for repealing several discriminatory laws, including the Lepers Act, 1898.

With persistent sensitization and advocacy from TLMTI, the 20th Law Commission of India, under the chairmanship of Justice (Retired) A.P. Shah released a report that recommended the repeal of the Lepers Act (Act 3) of 1898, calling it “completely out of sync with the modern understanding of the disease and its treatment.”

At the request of the Law Commission, in 2015, TLMTI, with support from the Vidhi Centre for Legal Policy, made a submission on other obsolete laws applicable to persons affected by leprosy. Following receipt of the submission, the Commission recommended amending and repealing discriminatory laws, and framed a new legislation to safeguard the rights of persons affected by leprosy and their family members, titled Elimination of Discrimination against Persons affected by Leprosy (EDPAL) Bill, 2015.

In 2018, the Vidhi Centre for Legal Policy and Advocate Pankaj Sinha filed writ petitions in the Supreme Court, challenging discriminatory provisions in Union government and State laws. In response, the Supreme Court noted that “leprosy is absolutely curable” and asked the Union government and States to delete all such laws.

Following the Supreme Court order, the Union government took a landmark decision in 2019 by passing the Personal Laws (Amendment) Bill, 2018, in Parliament. This action amended five Acts, making it illegal to use leprosy as a ground for divorce or separation. Demonstrating urgency, the then Union Minister of Health wrote to all the State governments to repeal discriminatory laws in their jurisdictions.

As of April 2023, the Union government and States have collectively repealed 31 discriminatory provisions. There are still 88 discriminatory provisions remaining in the form of acts, statutes, and rules in 22 states. More than 50% of these provisions were introduced between 1900 and 1980, before the World Health Organization’s 1981 recommendation established multidrug therapy as a new global standard for leprosy treatment.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has recommended that India repeal all discriminatory laws pertaining to leprosy. WHO has also emphasized the importance of amending these laws as they perpetuate stigma and hinder leprosy eradication efforts. The Ministry of Health and Family Welfare in India, in their previous and current strategies for leprosy eradication, highlighted the need for non-discriminatory laws. The International Federation of Anti-Leprosy Associations (ILEP) and the Sasakawa Health Foundation have been actively sensitizing policymakers about the significance of repealing these laws. This concerted effort aims at promoting equality, eliminating stigma, and safeguarding the rights and well-being of individuals affected by leprosy.

To learn more about repealing discriminatory laws, please write to nikita.sarah@leprosymission.in.

ANNOUNCEMENT

Tribute to APAL leader Venu Gopal (1952-2023)

The *Leprosy Bulletin* is saddened to announce the passing of Venu Gopal, a person affected by leprosy and social worker in India, who also served as the vice president and CEO of the Association of People Affected by Leprosy (APAL). For Goodwill Ambassador Sasakawa, Venu Gopal was an irreplaceable comrade in the fight against leprosy and related stigma and discrimination. The *Bulletin* is grateful to APAL, and especially to Mohan, for writing this tribute.

Venu Gopal (seated) with participants in a youth forum workshop on leadership held in Mumbai.

Venu Gopal was an Indian social worker who sacrificed his whole life to advocate for persons affected by leprosy and their families to live with dignity, and he made it easy to include persons affected by leprosy in mainstream society.

He was born in 1952 in Andhra Pradesh and advanced to higher education. He was affected by leprosy during his second year of college, and therefore was unable to finish his degree. After his hospital treatment ended, he coped with stigma and discrimination by leaving home and living in various leprosy colonies in different places in India for survival. He observed the plight of his fellow sufferers, their poverty, and their miserable way of living. Separated from their families, people were living in the leprosy colonies in unhealthy conditions without even bare necessities. He observed that there were no changes in their lives over many years. They depended on begging, and lived without any new hope for the future. The unchanging situations around him and his fears for his own future made him depressed for many years.

One day, he was fortunate to meet some social workers who were standing up for persons affected by leprosy. Their rights-based language and their thought patterns brought out the consciousness in him. He started attending various capacity-building meetings and did small jobs to survive.

The great leaders' introductions and associations, reading more revolutionary books, and personal experiences made him a leader to give a voice to the voiceless. With the support of Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, and Dr. PK Gopal, he got an opportunity to join the National Forum and Association of People Affected by Leprosy (APAL) to serve persons affected by leprosy and their families directly in leprosy colonies of 16 of India's 28 states.

He was a great public speaker, and he provided his services and worked for socio-economic empowerment and welfare of persons affected by leprosy as the Vice President and CEO of APAL. His down-to-earth nature, simplicity, and high regard for women were examples to all fellow leaders, and he became a role model for the leprosy community. His efforts to bring more than 800 leprosy colonies under one organization (APAL) were immense and indescribable. He always improved the relationship or network between the colonies and leaders working for persons affected by leprosy. His fearless and tireless services during the hectic time of COVID-19 and the "Don't Forget Leprosy" campaign were unforgettable.

Venu Gopal passed away on April 30, 2023. APAL's current president, Maya Ranavare, said that "APAL lost a great intellectual and man of knowledge. During his tenure, he spent more time in the field than with his family. He always used to say that when we get rid of our fear completely and live along with mainstream society, and when we can provide for ourselves while living with dignity and good character, then we will be able to experience independence. We will never forget his vision to gain gender equality and involve youth in leprosy services. We believe that he is always with us and guides us spiritually."

Venu Gopal (third from left) with APAL's Executive Committee members during a collaboration meeting with the Sasakawa-India Leprosy Foundation (S-ILF) in Delhi.

AMBASSADOR'S JOURNAL

Meeting with health leaders at the 76th World Health Assembly

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa traveled to Geneva, Switzerland, to meet with health leaders from around the world at the 76th World Health Assembly. He listened as leaders described the leprosy situation in their countries, and he asked for their cooperation in achieving a world without the disease and related problems.

Over five days, May 22-26, the Goodwill Ambassador met with health ministers and delegates from 17 countries as well as Dr. Tedros Adhanom Ghebreyesus, WHO Director-General; WHO regional directors; Volker Türk, UN High Commissioner for Human Rights; and Martin Chungong, Secretary-General of the Inter-Parliamentary Union (IPU).

With Dr. Tedros Adhanom Ghebreyesus, WHO Director-General. The Goodwill Ambassador updated the Director-General on his activities, including plans for restarting visits to leprosy endemic countries, organizing an international conference in Bergen in June, and encouraging a national conference in Brazil.

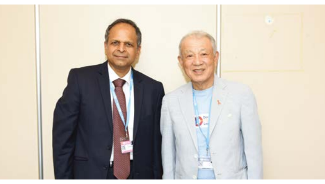
With Mr. Volker Türk, UN High Commissioner for Human Rights. The High Commissioner thanked the Goodwill Ambassador for his efforts over many years, and expressed his desire to cooperate in solving the human rights issue of discrimination against persons affected by leprosy and their families.

Americas - With Dr. Jarbas Barbosa, WHO Regional Director for the Americas. Dr. Barbosa is from Brazil, where the Goodwill Ambassador hopes there will be a national conference in the near future. Dr. Barbosa agreed to give his support to the conference as WHO Regional Director.

Brazil - With, at left, Dr. Nesio Fernandes, Secretary of Primary Health Care; Dr. Nísia Trindade Lima, Minister of Health; and Dr. Ethel Maciel, Secretary of Health and Environment Surveillance. The Primary Health Care Secretariat and the Health and Environment Surveillance Secretariat are the two divisions of Brazil's Ministry of Health responsible for Hansen's disease policies.

Pakistan - With, from left, Dr. Palitha Mahipala, WHO Country Representative, Dr. Malik Muhammad Safi, former Director General of Health, and Dr. Baseer Achakzai, current Director General of Health. Discussed awareness-raising in urban and rural areas in preparation for the Goodwill Ambassador's first visit to Pakistan.

Bangladesh - With Mr. Zahid Maleque, Minister of Health (left) and Dr. Md. Anowar Hossain Howlader, Secretary of the Health Services Division (right). Agreed that the first national conference, held in 2019, should be followed up by a second national conference as soon as possible.



India - With Mr. S Gopalakrishnan, Additional Secretary, Department of Health and Family Welfare. Discussed cooperation for eliminating discriminatory laws and strengthening activities in northeastern India.

Indonesia - With Mr. Setiaji, S.T., M.Si., Chief of Digital Transformation Office. Indonesia will consider implementing skin checks by health workers in model areas.

With Mr. Martin Chungong, Secretary-General of the IPU.

SASAKAWA LEPROSY HANSEN'S DISEASE INITIATIVE

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Publisher Yohei Sasakawa
Executive Editor Takahiro Nanri

Editorial Office 5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku, Tokyo 107-0052 Japan
Tel: +81-3-6229-5377 Fax: +81-3-6229-5388
leprosybulletin@shf.or.jp

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