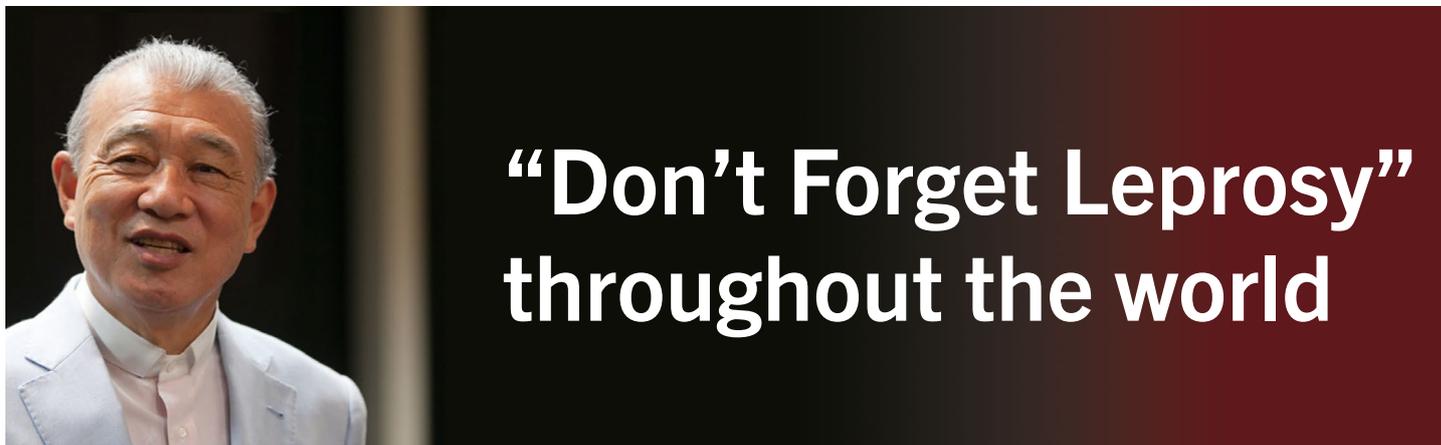


LEPROSY BULLETIN

NO. 110 AUGUST 2022



Message from the ambassador

When I heard that a friend of mine in Nepal was planning to climb Mt. Everest in May this year, I had the idea to ask him to have his photograph taken at the summit with the message "Don't Forget Leprosy." At the recent World Health Assembly, I showed this photograph to Dr. Tedros Adhanom Ghebreyesus, the director-general of the World Health Organization, as well as health ministers when I asked for their cooperation in eliminating leprosy. I was pleased to receive many positive responses.

However, as a person whose personal motto is "unity of knowledge and action," I wondered about simply asking someone else to climb. I knew that at age 83 I would not be able to climb Mt. Everest, but I started to think about climbing Japan's tallest mountain, Mt. Fuji, and showing the "Don't Forget Leprosy" message myself. I began training immediately, and at 4:42 a.m. on Aug. 4, I successfully reached the summit.

Eliminating leprosy from the world is my life's work. Over the past half-century, I have traveled to more than 120 countries around the world to promote elimination of the disease and discrimination against persons affected by leprosy and their family members. Just when I felt that we were on the verge of reaching this goal, the COVID-19 pandemic hit. As a result, leprosy control measures in many countries have regressed, and discrimination against persons affected by leprosy still persists in many areas.

I hope that when you turn the page and see the photo of me, an 83-year-old "young" man at the top of Mt. Fuji holding a banner amid gale-force wind, you will feel inspired to join my Don't Forget Leprosy campaign.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

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Director and Conductor, Achinivu-Harcourt Whyte Choral Association

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

INITIATIVE NEWS



WHO Goodwill Ambassador Yohei Sasakawa spreading the "Don't Forget Leprosy" message from the top of Japan's tallest mountain, Mt. Fuji (3,776 meters). Sasakawa reached the summit at 4:42 a.m. on Aug. 4, 2022, following a successful climb from the fifth station at age 83.



Mingma David Sherpa, Guinness World Record holder and executive board member of the Nepal Mountaineering Association, holding a "Don't Forget Leprosy" poster on the peak of Mt. Everest, the tallest mountain in the world (8,848.86 meters), on May 15, 2022.

Survey projects supported as part of Don't Forget Leprosy campaign send in reports

Sasakawa Leprosy (Hansen's Disease) Initiative has been running a campaign called "Don't Forget Leprosy" since August 2021 to send the message that leprosy must not be overlooked amid the COVID-19 pandemic. As a part of the campaign, the Initiative provided grants for surveys covering one or more of three themes: 1) the impact of the coronavirus pandemic on persons affected by leprosy and their family members; 2) discrimination against persons affected by leprosy; 3) the socio-economic situation of communities of persons affected by leprosy.

Between January and June 2022, 14 organizations from 10 countries conducted surveys. Based on their reports, the Initiative recognizes the following achievements:

- Participating organizations laid a foundation for the development of an evidence-based long-term plan to eliminate prejudice and discrimination against persons affected by leprosy and their family members living in the general community.
- Participating organizations obtained important evidence that can be used to call for collaboration and support from relevant government entities and NGOs working in related fields.
- Participating organizations established foundational evidence for persuading others that persons affected by leprosy, who are marginalized and vulnerable

even when all is normal, suffer acutely during times of crisis.

- Participating organizations contributed to raising awareness of leprosy among government officials and health care workers.
- Participating people's organizations of persons affected by leprosy gained new experiences and knowledge.

Further details about three of the survey projects are shared on pages 3-5 of this issue of the *Leprosy Bulletin*. The Initiative is also considering setting up a future opportunity for the results of each survey project to be shared.



The Bogura Federation's project in Bangladesh used the digital platform KoBo Toolbox for data collection. Orientation included a practical demonstration in the field.

REPORT



PerMaTa South Sulawesi is the largest provincial branch of PerMaTa Indonesia, which is a nationwide people's organization established in 2007 to eliminate stigma and discrimination associated with leprosy.

<https://www.permatasulsel.com>

Yayasan Dedikasi Tjipta Indonesia (YDTI) is an Indonesian non-profit organization that works in close partnership with PerMaTa South Sulawesi to build the capacity of persons affected by leprosy.

<https://ydti.org>

Persons affected by leprosy in Indonesia investigate possible human rights violations

As a stigmatized disease, leprosy affects all aspects of a person's life, and experiences with social marginalization and discrimination can continue long after the disease has been cured. When persons affected by leprosy have attempted to draw attention to their experiences, they have often been turned away because they lack the knowledge and power to prove that their human rights have been violated.

With the support of the Sasakawa Health Foundation, PerMaTa South Sulawesi–YDTI conducted a pilot project with the overall aim of enabling persons affected by leprosy and their organizations to take action against violations of their rights. A field team of six persons affected by leprosy were selected from among PerMaTa's members. Following a series of workshops and usage of a questionnaire to identify instances of possible human rights violations, the team developed five "cases" for further investigation.

Each case was framed in terms of the suspected human rights violation, such as "student expelled from school because of leprosy" or "neighborhood prohibits the use of the community well because of leprosy." The team gathered information in the village for 10 days, spending 2-3 days on each case, and then met in a workshop to analyze findings, form conclusions, and discuss next steps.

Proving clear violations of specific laws was difficult. For example, in the case of "student expelled from school because of leprosy," the team found out that the boy was still registered as a student, and so his expulsion was not official. In the words of the report: "It turned out that most of our cases were not very clear violations of specific laws but consisted of many vague aspects in which many sides were involved. In our five cases, it was always the ignorance and prejudices of those involved that led to the incident. Awareness raising and support to solve the problems locally were needed, not to bring the case to court."

Overall, the project demonstrated that, given the right training, persons affected by leprosy are well-suited to investigating cases of potential human rights violations.

Based on the experiences and insights gained, a set of guidelines has been produced in English and Indonesian with the hope of encouraging other organizations to investigate cases they encounter.



Investigators made use of the EMIC stigma scale to measure the level of stigma in the community, and they found that older people tend to be more prejudiced against persons affected by leprosy.



Results of the investigations were presented to officials of the province of South Sulawesi and Jeneponto's health department. The officials took careful note of the findings.



Saksham Kushthanteya Swabhimani Sanstha (SKSS), India

SKSS is a community-based (non-colony) organization of, for, and by persons affected by leprosy in Maharashtra, India. The organization strives for an inclusive society wherein persons affected by leprosy and their family members are able to live dignified lives on par with fellow citizens.

<https://www.skssleprosy.org>

Survey of persons affected by leprosy and their family members in India's Chandrapur and Gadchiroli districts

Between January and May 2022, Saksham Kushthanteya Swabhimani Sanstha (SKSS), a community-based organization of persons affected by leprosy, carried out a project to collect data on the impact of leprosy and COVID-19 on the lives of persons living in tribal/rural communities in the Chandrapur and Gadchiroli districts of Maharashtra, India. The project was funded by a grant from the Sasakawa Health Foundation as part of its Don't Forget Leprosy campaign and implemented with technical support from SKSS's partner organization, ALERT India.

The 5-month project involved a workshop to develop survey tools and a survey plan; orientation and capacity-building for field investigators; a survey; and a workshop to plan post-survey interventions.

The districts where the survey was conducted, Chandrapur and Gadchiroli, are among the top 10 leprosy-impacted districts in India. A total of 1,910 participants were reached through personal interviews and focus group discussions, including 595 persons affected by leprosy, 605 family members, and 640 members of the general population (as a control group).



A project team member interviewing a person affected by leprosy.

Regarding the health impact of COVID-19, only 2% of persons affected by leprosy and their family members had been infected by the virus versus 7% of the control population (self or family). However, health service accessibility was affected by the pandemic, and 10% of respondents with lepra reaction and 9% with disability said that there had been disruptions to the supply of medicines or leprosy-related services.

Most of the persons affected by leprosy who were interviewed belong to the lower socio-economic strata of society. More

than half of them do laboring jobs to earn a living, and only 11% have a family income of more than 10,000 rupees per month. Their sources of livelihood were badly disrupted during the pandemic; 14% said that their income has yet to return to pre-pandemic levels.

The study also confirmed the existence of stigma and discrimination, with 23% (138/595) of persons affected by leprosy saying that they experienced it, either recently or in the past. Their experiences include being isolated within the family and being pressured to stay in a colony. Nearly half of those reporting stigma and discrimination (62/138) experienced it in relation to marriage, including being abandoned by a spouse and rejection while looking for a life partner for themselves or a family member.

Participating in the project has strengthened SKSS as an organization and improved its capacity to undertake field-level, evidence-based intervention projects. The organization is planning to use the results in advocacy with policy makers.



SKSS and ALERT India, together with the district-level National Leprosy Eradication Programme (NLEP) unit, organized a Rangoli art exhibition on leprosy, where attendees pledged to end stigma and discrimination towards persons affected by leprosy and their family members.



Following the survey, SKSS and ALERT India conducted a 3-day workshop on developing a post-survey, evidence-based intervention plan to address issues impacting persons affected by leprosy living in the community.

LETTER



Nwanneka Udoye
Research Assistant, RedAid Nigeria

Between January and May 2022, Nwanneka Udoye worked as a research project officer on a study funded under the Don't Forget Leprosy campaign to determine factors affecting the socio-economic status of persons affected by leprosy in southern Nigeria. RedAid Nigeria is a sister organization of the German Leprosy and TB Relief Association (GLRA).

<https://nigeria.red-aid.org>

Experience as a research project officer changed my life

My name is Nwanneka Udoye, and I am a 42-year-old female science laboratory technology graduate. I live in Enugu, Nigeria. I am a person affected by leprosy, and I have had struggles with stigma and discrimination. Waking up one morning to observe obvious changes on one's skin as a result of leprosy can be devastating! At first, I withdrew from society, crawled into a shell, and lost interest in life.

Thanks to organizations like the Sasakawa Health Foundation (SHF) and the German Leprosy and TB Relief Association (GLRA), I had the privilege of working as a research project officer as part of the Don't Forget Leprosy campaign.

My job was to coordinate a project under the skillful mentoring and supervision of GLRA technical team members. This offered me the opportunity to travel to other states. I visited five out of the six states in southern Nigeria covered by the project.

In the process of data collection, I interviewed several individuals whose situations as persons affected by leprosy were worse than mine. An adage says, "I cried because I had no shoes until I met a man who had no feet." Through this experience, I can now confidently say that I don't have a problem.

This project changed me — not just in terms of my mental wellbeing or socio-economic situation — but by holistically influencing how I approach awareness-raising around leprosy. I also acquired some research and project management skills such as data collection and activity reporting. Now I can conduct key informant interviews and lead focus-group discussions. Recently, another research group asked me to assist them in inviting persons affected by NTDs to participate in a different data collection project.

Persons affected by leprosy are greatly challenged socio-economically, not because they are unproductive, but because they have limited opportunities to utilize their potential and expertise. Those of us with obvious deformities suffer more because of the stigma and discrimination erroneously attached to our condition.

Thanks to SHF for providing the right opportunity through its global Don't Forget Leprosy campaign. And thanks to GLRA for providing the right platform to spread awareness of leprosy and

for promoting a people-centered approach. They brought me back into society and out of my shell.



Over 25 representatives of persons affected by leprosy across Ebonyi State, health workers, and GLRA/SHF project team members gathered at St. Patrick's Leprosy Referral Hospital to explore the current socio-economic situation of persons affected by leprosy amid persistent stigma and the COVID-19 pandemic.



GLRA/SHF Research Project Officer Nwanneka Udoye, a person affected by leprosy, traveled to Ebonyi State in southeast Nigeria with other team members to interview persons affected by leprosy on the factors affecting their socio-economic well-being, current stigma situation, and effects of COVID-19.

VIEWPOINT



Bill Gallo
Secretariat Director, Global Partnership for Zero Leprosy (GPZL)

Bill Gallo has over 30 years of experience with the Centers for Disease Control and Prevention (CDC) in public health program management, policy, and administration. The Global Partnership for Zero Leprosy (GPZL) is a coalition of people committed to ending leprosy, also known as Hansen's disease.

zeroleprosy.org

The Abidjan Declaration: Commitment to Zero Leprosy in Côte d'Ivoire

In the first week of June, the National Leprosy Programme of Côte d'Ivoire hosted meetings to mobilize the resources needed to end leprosy in the country by 2030. Fondation Raoul Follereau and other partners provided key support for these meetings, which resulted in substantial funding commitments to support the plan.



Technical meeting held on June 1, 2022. Hosted by the National Leprosy Programme of Côte d'Ivoire, Fondation Raoul Follereau, and the Global Partnership for Zero Leprosy.

I was fortunate to attend this impressive program in Abidjan. Over the past two years, the Global Partnership for Zero Leprosy (GPZL) has worked alongside the National Leprosy Programme of Côte d'Ivoire as it implemented the Zero Leprosy Country Model. Alongside national and international partners, the Programme, led by Dr. Marcellin Assie, developed a roadmap and an action plan to achieve zero leprosy in Côte d'Ivoire by 2030. The next step was to mobilize the resources needed to implement the plan.



Prime Minister Patrick Achi spoke at a resource mobilization event at the Radisson Blu Hotel in Abidjan on June 2, 2022. He expressed commitment to the vision of a leprosy-free Côte d'Ivoire and support for the country's new Zero Leprosy Action Plan.

The Government of Côte d'Ivoire hosted a resource mobilization event that included Prime Minister Patrick Jérôme Achi on June 2, 2022. The prime minister expressed

support for Côte d'Ivoire's Zero Leprosy Action Plan, and government and non-governmental partners stepped up to fund the activities needed to achieve no disease, no disability, and no discrimination or stigma.

These partners expressed their support by signing the Abidjan Declaration, a commitment to mobilize the resources, both national and international, necessary for the implementation of the interventions of the Zero Leprosy Action Plan. The declaration also outlines how the Zero Leprosy Action Plan integrates with Côte d'Ivoire's plan to fight Neglected Tropical Diseases with skin manifestations in alignment with the WHO 2021-2022 Roadmap for Neglected Tropical Diseases.

I was proud to sign the Abidjan Declaration alongside Côte d'Ivoire's Minister of Health, Public Hygiene and Universal Health Coverage, as well as the WHO country representative, and leaders from Fondation Raoul Follereau, Anesvad Foundation, American Leprosy Missions, Sasakawa Health Foundation, Novartis, Hope Commission International, Ivorian Association of Raoul Follereau, Association of Persons Affected by Leprosy, KED Foundation, Effect Hope, and Sightsavers.

The National Leprosy Programme of Côte d'Ivoire has set an exciting example of what commitment to the zero leprosy vision can look like. We look forward to our continued partnership with the National Leprosy Programme of Côte d'Ivoire as they move from the strategic development stage into program implementation.



Members of the Zero Lepre Committee and signatories of the Abidjan Declaration join Prime Minister Patrick Achi in supporting Côte d'Ivoire's Zero Leprosy Action Plan.

REPORT



Ashish Shukla
Communications Manager, Disabled Peoples' International (DPI)

Disabled Peoples' International (DPI) is a network of over 120 national organizations committed to protecting the human rights of persons with disabilities and promoting their full and equal participation in society. Ashish Shukla, based in New Delhi, has been working with DPI since 2016.

<https://disabledpeoplesinternational.org>

COSP15 side event on participation of persons with invisible and neglected disabilities in climate action and disaster risk reduction

In conjunction with the 15th session of the Conference of States Parties (COSP15) to the Convention on the Rights of Persons with Disabilities (CRPD), Disabled Peoples' International (DPI) partnered with the Sasakawa Health Foundation (SHF) to hold an online side event on June 16, 2022. The side event focused on the session's sub-theme about participation in climate action and disaster risk reduction, and it emphasized enabling meaningful participation of persons with invisible and neglected disabilities such as leprosy. Additionally, organizers intended the event to build states' awareness of the diversity of disabilities so that all persons will be provided with equal access and opportunities under national laws in compliance with the CRPD.

Major takeaways from the event include the following points:

- Community engagement is a key strategy for simultaneously preventing and responding to outbreaks and natural disasters because communities have an accumulated and action-oriented knowledge about their territory and people that can enhance the efficiency of states' responses to crisis.
- The implementation of Article 11 of the CRPD¹ is inseparable from the participatory principle that frames the entire convention. Notwithstanding, the word "participation" is often used in discourse, but seldom put into practice. There are issues of recognition and access. For example, persons affected by leprosy are not recognized as persons with disabilities in many national frameworks. These issues are barriers to participation and must be addressed as priority matters.
- The COVID-19 pandemic opened a window for strengthening digital health initiatives. Digital health can increase consultation possibilities in remote areas without doctors.
- Disabled people must be involved in planning and design stages. Only then can we have a resilient structure to

take care of all four stages of a crisis: rescue, relief, rehabilitation, and restoration.

- States and all key actors must recognize leprosy as a disability issue, and persons affected by leprosy should be allowed to participate in all policy formulation processes.
- "Participation" alone should not be the goal. We should aim for "effective participation," which is "participation as the means to achieve something."
- One of the biggest barriers to making sure that no one is left behind is the lack of information, specifically disability disaggregated data about the impact of disaster and climate change on persons with invisible and neglected disabilities.
- Lack of information contributes to lack of awareness, stigma, and fear.
- There are barriers related to intersectionality of gender, ethnicity, and poverty.
- Accessibility is another huge issue; there are barriers preventing access to built infrastructure, cyclone shelters, wash points, transportation, communication, early warning, technology, and so on.
- Mobilization and strengthening of disabled people's organizations are important.
- Organizations for persons with disabilities should include persons affected by leprosy.
- Need to support and promote champions of inclusion from the invisible and neglected disability sector.

A video recording of the event and details about sponsors and speakers have been posted to the Sasakawa Leprosy (Hansen's Disease) Initiative website.

<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/1017-2/>



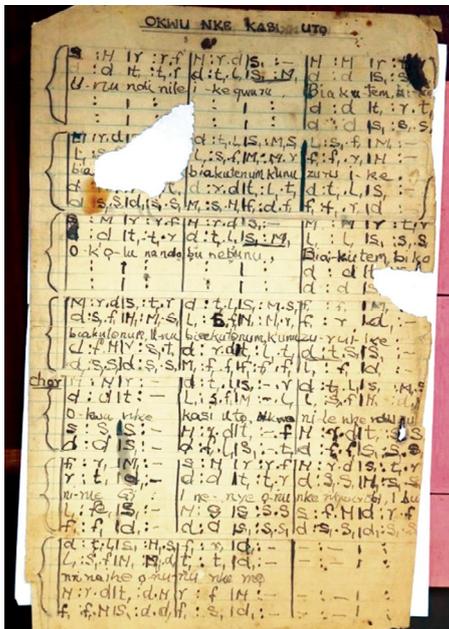
¹ Article 11 (Situations of risk and humanitarian emergencies): "States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters."

SPOTLIGHT

Ikoli Harcourt Whyte's songs to be published in dual notation with lyrics in English translation

Nigeria's best-known person affected by leprosy, Ikoli Harcourt Whyte (1905-1977), received his diagnosis in 1914, when lack of treatment was expressed in the Igbo saying: “*Onwu bu Ogwu ya* (Death is its cure).” He became one of the first resident patients of the Uzuakoli Leprosy Centre when it was jointly opened in 1932 by Britain’s Methodist Missionary Society and Eastern Nigeria’s government authorities. While a resident, Whyte developed into a prolific composer of what anthropologist and historian John Manton has called “songs of worship and wonder.” Searching YouTube for “Harcourt Whyte” will bring up many recordings of his songs along with comments underneath that testify to the power of his lyrics. Fans of the British rock band Coldplay may be familiar with Whyte's "Otutu Nke Chukwu" from the sample used in “Champion of the World.”

Whyte strongly believed that he had life-changing messages for the world, and to emphasize these messages, he insisted that his songs be performed without any form of accompaniment. He wrote his songs in tonic sol-fa notation, which was



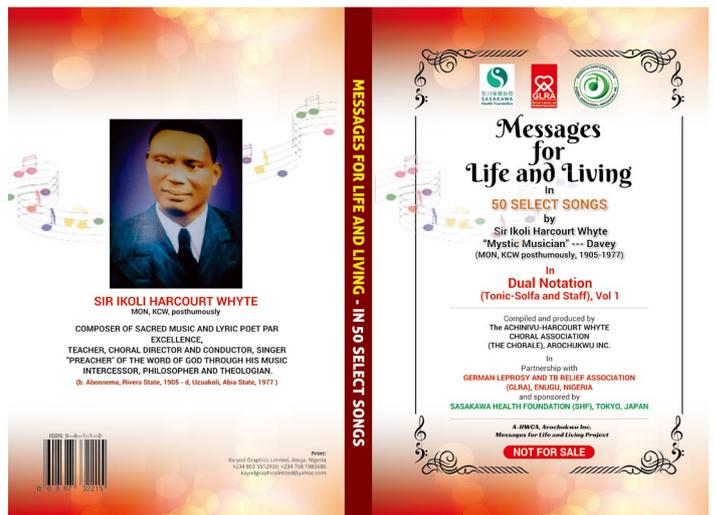
Example of tonic sol-fa notation. The manuscript's title, handwriting, harmony, and style suggest that the song was composed by Ikoli Harcourt Whyte, but more research is needed for confirmation.

developed for teaching singing and sight reading, but is unfamiliar to many musicians today. This notation system — along with lyrics in Igbo, inaccuracies introduced when copies were made by hand, and damage caused by termites and civil war — has blocked Whyte’s messages from reaching their full potential for spreading worldwide.



A. Kanu Achinivu, director and conductor of the Achinivu-Harcourt Whyte Choral Association, Arochukwu Incorporated.

With the support of the Sasakawa Health Foundation, Whyte’s protégé, A. Kanu Achinivu, has been leading an effort to transcribe his compositions into staff notation and to translate many of the songs’ lyrics into English. The resulting collection of sheet music will soon be published as *Messages for Life and Living*. In Achinivu's words, this collection "is regarded by my organization and me as Nigeria's gift, a wonderful gift, to the world of Music, Christendom and the global community."



The proposed cover for *Messages for Life and Living*, a collection of 50 select songs composed by Ikoli Harcourt Whyte, compiled and produced by the Achinivu-Harcourt Whyte Choral Association in partnership with the German Leprosy and TB Relief Association and with the support of the Sasakawa Health Foundation.

