

# LEPROSY BULLETIN

NO. 120 APRIL 2024



## Pursuing zero leprosy in Asia and Africa

### Message from the ambassador

The Sasakawa Health Foundation (SHF), established in 1974 under the umbrella of The Nippon Foundation for taking action toward a leprosy-free world, will mark its 50th anniversary on May 4, 2024. SHF's first chair, Morizo Ishidate, was a former professor of pharmaceutical sciences at the University of Tokyo known for being the first person in Japan to synthesize Promin, a drug treatment that kickstarted the transformation of leprosy into a curable disease.

During the 50 years that SHF has been operating, much has changed. Drugs for treating leprosy are now distributed free of charge throughout the world, and the number of patients has plummeted. The United Nations General Assembly adopted a resolution to eliminate discrimination against persons affected by leprosy and their family members, and awareness that leprosy is a human rights issue has spread worldwide. I am proud to say that I played a small role in achieving these milestones.

However, the fight against leprosy continues. Leprosy cases are still appearing in nearly 140 countries, and there are many more cases that remain hidden. Persons affected by leprosy and their family members are still forced to cope with unjustifiable stigma and discrimination. Because of the impact of COVID-19 and other factors, I am concerned that we will not reach WHO's targets for 2030. As Chairman of The Nippon Foundation, I will do what I can to direct resources to the achievement of these targets. As the WHO Goodwill Ambassador for Leprosy Elimination and the Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy, I am completely committed to realizing a leprosy-free world.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

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

## REPORT



**Dr. Aya Tobiki**  
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Aya Tobiki is in charge of the Sasakawa Health Foundation's medical program and history preservation program for Hansen's disease. She holds a doctoral degree in Policy Studies.

<https://www.shf.or.jp/en/leprosy/>

## Accelerating efforts toward elimination in Comoros

The Union of the Comoros is an archipelago island nation in the Indian Ocean's Mozambique Channel, which separates Madagascar from mainland Africa. In 2022, the country's population of approximately 837,000 people had 263 new cases of leprosy, of which 76 (28.9%) were child cases.<sup>1</sup> Adjusted to per million population, the new case detection rate becomes 314.2, which is much higher than the comparable rates of Brazil (91.2), India (73.3), and Indonesia (45.2), the three countries with the highest number of new cases. Comoros is a highly endemic country with one of the highest rates of infection in the world.

The sovereign state comprises three main islands: Ngazidja, Mwali, and Nzwani, known internationally by their French names as Grande Comore, Mohéli, and Anjouan. Currently, the government is organized as a federal presidential republic, with a president leading Comoros as head of state and government and three governors in charge of the islands. Of the three islands, Anjouan has the highest

number of leprosy patients, with a new case detection rate per million population of 530.

When WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Comoros in 2018, he observed the high proportion of child patients and evidence of severe poverty firsthand. The following year, in 2019, The Nippon Foundation (TNF) and the Sasakawa Health Foundation (SHF) supported the Comoros Ministry of Health through the World Health Organization (WHO) to launch a leprosy elimination campaign to detect cases and treat them with multidrug therapy. This Maxi-Leprosy Elimination Campaign (Maxi-LEC) was developed and implemented under the committed leadership of President Azali Assoumani. At the launch ceremony, he declared that Comoros would achieve elimination of leprosy as a public health problem by 2025.

According to WHO, "The campaign achieved massive community mobilization resulting in the screening of around 25,000 persons (7% of the total population of Anjouan), and doubled leprosy annual detection from 275 new cases of leprosy in 2018 to 600 new cases in 2019."<sup>2</sup>

The Maxi-LEC as well as other smaller scale campaigns that were carried out through WHO with support from TNF and SHF have covered 34 of Anjouan's 101 villages. Active case finding has also been carried out separately by the Damien Foundation, a Belgium-based organization with over 40 years of experience fighting leprosy in the Comoros islands, in 34 other villages.<sup>3</sup>

As of the start of 2024, there were 33 remaining villages where no active case finding was taking place. Aiming for island-wide screening of Anjouan, SHF and the Damien Foundation commenced collaboration in March 2024 to conduct active case finding in 15 of the remaining villages for a three-year period concluding in April 2027.

According to the Damien Foundation, past case detection data indicates that, in 2019, door-to-door screening found 39.86 new cases per 10,000 population (41% child cases)



Credit: OCHA, CC BY 3.0, via Wikimedia Commons.

<sup>1</sup> World Health Organization, "Global leprosy (Hansen disease) update, 2022: new paradigm – control to elimination," *Weekly epidemiological record* 98, no. 37 (September 15, 2023): 409–430.

<sup>2</sup> "Leprosy elimination in the Comoros," World Health Organization, last modified November 15, 2019, <https://www.who.int/news-room/feature-stories/detail/leprosy-elimination-in-the-comoros>.

<sup>3</sup> This includes the PEOPLE (Post Exposure Prophylaxis for Leprosy in the Comoros and Madagascar) project and BE-PEOPLE (Bedaquiline enhanced exposure prophylaxis for Leprosy in the Comoros) projects conducted by Damien Foundation.

compared to 13.75 new cases per 10,000 population (10% child cases) detected through campaigns. The conclusion based on this data is that, in Anjouan's villages, door-to-door screening is a more effective method for finding new cases.

In cooperation with the Ministry of Health, five teams of community health workers and nurses have started conducting door-to-door screenings under the supervision of a central medical team. Families that have one or more persons diagnosed with leprosy are receiving a nutrition kit that provides about six months' worth of staple food. The hope is that the kit will help to reduce progression of the disease in those who have been infected and incidence of disease in their close contacts.

The project launched with a ceremony on March 9. Approximately 150 people attended the event, including Dr. Nimer Ortuño-Gutiérrez, Medical Advisor, Damien Foundation; Dr. Younoussa Ansoumani, Comoros Branch Representative of the Damien Foundation; and the honorable guests of Dr. Zaidou Youssef, Governor of

Anjouan; Dr. Aboubacar Said Anli, Secretary General of the Ministry of Health; Dr. Aboubacar Mzembaba, National Coordinator for Leprosy and Tuberculosis; Dr. Diarra Abdoulaye, WHO Representative for Comoros; village chiefs; and medical personnel. Goodwill Ambassador Sasakawa sent a video message in which he expressed his respect and gratitude for the dedication of the Damien Foundation and the Ministry of Health along with his wish for Anjouan to become a model case showing that zero leprosy can be achieved. He is counting on the dedication of the people involved in the project and the commitment of Anjouan's leaders to bring the benefits of early detection and treatment to as many infected persons as possible.

This project will help to establish a rhythm of early detection and early diagnosis in the 15 villages and will increase the percentage of Anjouan's villages participating in active case detection activities to over 80%. SHF hopes that this project will assist the Union of the Comoros as it moves forward along the path toward zero leprosy.



Approximately 150 people attended the launch ceremony on March 9, 2024, in Mutsamudu, Anjouan's capital city.



The community health team conducts door-to-door screening.



Seated at the table, from left to right, are Dr. Younoussa Assoumani, Representative Damien Foundation Comoros; Dr. Grillone Saverio, Honorary Consul of Italy in Comoros, Damien Foundation; Mr. Zarouki Bouchrane, Mayor of Mutsamudu, the capital of Anjouan; Mr. Saindou Ali Assane, Secretary General of the Anjouan Governorate; Dr. Aboubacar Said Anli, General Secretary of Health, Ministry of Health, Comoros; Dr. Zaidou Youssef, Governor-elect of Anjouan; Dr. Saindou Ben Ali Mbaé, Director General Ministry of Health, Comoros; Dr. Ansufoudine, Regional Director of Health, Anjouan; Ms. Maya Ponse, Researcher Institute of Tropical Medicine, Antwerp; Dr. Zahara Salim, Head of Dermatology, Leprosy and Tuberculosis Department Hombo Hospital, Anjouan; Dr. Aboubacar Mzembaba, National Coordinator for Leprosy and Tuberculosis, Comoros.



The community health team organized by the Damien Foundation and the Comoros Ministry of Health gathered for a photograph with the delegation from Damien Foundation headquarters.

## REPORT



**Klinton Malakar**  
Project Officer

**Advancing Leprosy and Disadvantaged Peoples Opportunities (ALO) Society**

Founded in Bangladesh in 2013, ALO Society is a registered national level NGO of persons affected by leprosy working toward a “society for all” where everyone knows their rights, has access to quality care, and can find opportunities to improve their livelihood.

<https://alosocietybd.org/>

## Empowering leprosy-impacted communities through education in Bangladesh

Bangladesh’s education system spans primary, secondary, higher secondary, and tertiary levels. Despite efforts to improve access and quality, dropout rates persist as a significant challenge. Primary dropout rates stand at 13.95% and higher secondary dropout rates reach 37.6%, according to the 2022 Bangladesh census and the Bangladesh Bureau of Educational Information and Statistics (BANBEIS), respectively. Poverty, limited access to schools in rural areas, and societal norms, especially regarding gender roles, contribute to these dropout rates. Moreover, the stigma surrounding leprosy exacerbates vulnerabilities, hindering affected families’ ability to support their children’s education.

In response to these challenges, the Advancing Leprosy and Disadvantaged Peoples Opportunities (ALO) Society initiated the “Education for Empowerment Project,” supported by the Sasakawa Health Foundation (SHF) and with technical expertise from The Leprosy Mission International-Bangladesh (TLMI-B). This project aims to empower individuals affected by leprosy and their communities through education.

Operating across seven districts, the project takes a holistic approach to community empowerment by addressing various needs. By prioritizing education, the ALO Society aims to uplift individuals and break the cycle of poverty and stigma. Through collaborative efforts, the project stands as a beacon of hope, offering a novel approach to community development.

In a complex socioeconomic landscape, targeted interventions are crucial. The Education for Empowerment Project seeks to bridge gaps in access and quality, providing a lifeline to marginalized individuals affected by poverty and leprosy stigma. Through innovative approaches and collaborative efforts, the ALO Society and its partners pave the way for a brighter and more inclusive future.

The project supports 100 students (37 male, 63 female) from vulnerable families affected by leprosy to pursue higher education. Sponsored students, in turn, provide free coaching services to 498 primary and high school students as well as non-formal education to 210 adult members of leprosy people’s organizations. The project also

offers training in leprosy case identification and teaching methods to sponsored students, enabling them to learn and disseminate this knowledge to others. Education materials were provided to adult learners and sponsored students to facilitate coaching setups. This active participation model has resulted in enhanced educational achievements and increased community engagement.

Despite challenges such as adapting to evolving teaching methods and political disruptions, the project has shown resilience. It has already shown significant impact and is changing mindsets within the community. Looking ahead, the project aims to expand its reach and impact by deepening community engagement, strengthening educational support systems, and advocating for sustainable change.

The Education for Empowerment project demonstrates the transformative potential of education to uplift marginalized communities and the ALO Society’s commitment to supporting the community in ways that result in lasting change.



A sponsored student teaches adult learners during an evening session at the Daragaw Leprosy and Disable Development Initiative in Hobigonj, Sylhet, on January 19, 2024.

## REPORT



**Chris Laing**  
Communications Manager  
Lepra

Founded in January 1924, Lepra provides a range of person-centered and holistic treatment services across India and Bangladesh to help reduce the physical, social, financial, and emotional impact of leprosy and lymphatic filariasis.

<https://www.lepra.org.uk/>

## Breaking the cycle of leprosy and poor mental health

Inequalities in healthcare, barriers preventing access to information, and disparities in education and socioeconomic opportunities inevitably mean that the world's most vulnerable communities face the greatest impact of poor mental health.

Persons affected by neglected tropical diseases (NTDs), such as leprosy, face perhaps some of the greatest challenges in maintaining their mental health, which is widely understood to have a direct effect on physical recovery. According to a mental health and NTD study published in *Leprosy Review*, one in two persons diagnosed with leprosy experiences depression and/or anxiety.<sup>1</sup>

Over the last decade, recognizing the important role of positive mental health for persons affected by leprosy, Lepra has developed a series of operational research projects that seek to integrate components for strengthening emotional health in leprosy and lymphatic filariasis treatment program design. One such project is “Mind to Heart” in Bangladesh.

Built on learning gained from projects such as Lepra's “Mental Motivators,” the Mind to Heart project is community-led. With funding from the Sasakawa Health Foundation, it is implemented in partnership with the Bogura Federation, a grassroots Community-Based Organization (CBO) supported by Lepra that brings together 101 community “self-support groups” in a network spread throughout Bangladesh's Bogura District.

During 2023, Phase 1 of the project aimed to support 300 persons affected by leprosy with grade 2 disability in the Bogura District. The project's initial goals included lowering levels of anxiety and depression alongside raising awareness. Improving access to community and specialist mental health services is a key element, along with widening the capabilities of the Bogura Federation to serve as a center of holistic care.

To reach the goals, three tiers of intervention were made available: 1) awareness raising and signposting (helping people understand, access, and navigate services that will improve their health) by Mental Motivators (community volunteers) for the lowest level of need; 2) professional

structured counseling for moderate need; and 3) specialist onward referrals for the highest level of need.

These Phase 1 activities, including mental health counseling, were well received by participants: 91% of survey participants stated that Mental Motivator support has been beneficial for their mental wellbeing and 73.7% indicated that their knowledge about mental health issues improved.

Phase 2, due to start in spring 2024, seeks to implement improvements based on lessons learned during Phase 1. In particular, this second phase will address the need for more intensive and longer-term therapeutic interventions, and it will seek to further strengthen the Bogura Federation, better enabling them to support the community's ongoing emotional health needs.

The Mind to Heart project demonstrates that there is no single intervention which can solve the issue of poor mental health. It is clear that a range of interventions are needed. With the interdependency of emotional, social, financial, and physical health for persons affected by leprosy clearer than ever, Mind to Heart will continue to be embedded into local healthcare structures, with the Bogura Federation leading sustainable improvements for years to come.



Tohomina received a house as a gift from the Honorable Prime Minister as a result of advocacy with government health and administration through the Mind to Heart project. Photo credit: Md. Waheduzzaman Polu, PM, LB, Bogura.

<sup>1</sup> Jennifer Mangeard-Lourme, Guillermo Robert de Arquer, Jayaram Parasa, Rajni Kant Singh, Naveen Sattle, and Radhika Mamhidi, “Depression and anxiety in people affected by leprosy and lymphatic filariasis: A cross-sectional study in four States in India,” *Leprosy Review* 91, no. 4 (2020): 367-382, <https://doi.org/10.47276/lr.91.4.36>.

# His Holiness Dalai Lama–Sasakawa Scholarship supports youth in India's leprosy colonies

✍️ Written in collaboration with the Sasakawa-India Leprosy Foundation (S-ILF)

The Dalai Lama–Sasakawa Scholarship was established in 2015 to support young people in India's self-settled leprosy colonies to pursue post-secondary education for a professional career. Although scholarship recipients are called "scholars," only applicants admitted to "professional courses" in job-related fields such as law, pharmacy, computer science, or hospitality are considered. The administering organization, Sakakawa-India Leprosy Foundation (S-ILF), calls the scholarship a "skills to empowerment program." The emphasis on practicality is tied to the goal of helping young people to secure well-paying, socially respected jobs that transform family circumstances and inspire the community.

In 2023, with funding from the Sasakawa Health Foundation, S-ILF provided scholarships to 26 students from eight states and one union territory. Of these 26 students, 14 were male (54%) and 12 were female (46%). A Bachelor of Technology degree attracted the most interest, with over one third (10/26) of the students choosing this course. Six students were awarded support for a master's degree, the highest number of

students aiming for an advanced degree since the scholarship program began.

A survey of the recipients revealed that young people in leprosy colonies must overcome numerous barriers to participation in higher education. In addition to the obvious barrier of low income, students lack opportunities to receive guidance about paths available to them. Experiences with leprosy-related stigma and discrimination can negatively affect self-esteem and make young people feel reluctant to share information about their background. Even with the financial support and mentoring of the scholarship program, some students are unable to complete their course.

To spread awareness of what is possible when opportunities, resources, hard work, and some luck come together, the *Leprosy Bulletin* is sharing the stories of three scholarship recipients from Jharkhand, a state in eastern India where leprosy remains endemic. The *Bulletin* is grateful to S-ILF for gathering this information.

## Sanjay Kumar Kalindi

### Diploma in Electrical Engineering, 2017-2019



Sanjay Kalindi is a resident of Lakarka leprosy colony, Dhanbad, Jharkhand. From childhood onwards, in one way or another he contributed to his family's income. He worked in ration shops and in internet cafes for very low compensation. His father,

who had leprosy, worked as a day laborer. His family did not have enough money to send him for further education.

Concerned about his future, he looked for options and found out about the scholarship program. He was selected to pursue a Diploma in Electrical Engineering. When he started working, he faced many challenges, but over time, his life changed completely.

His dedication and sincerity gained him and his family respect from fellow colony residents. He began earning enough that his father could quit his job and his family could

afford three meals a day. He was also able to buy them comforts and technology like a sofa set, a television, and a mobile phone. His mother is suffering from diabetes, and he was able to buy her medicine.

Now the colony children look up to him as a role model. He tries to give back by motivating them to study, and he urges parents to send their children to school instead of sending them to earn money. He also provides guidance and career counseling to youth worried about their future, and he encourages them to apply for the scholarship.

## Anil Mahato

### Bachelor of Education, 2017-2019



Anil Mahato was born in Ashadeep leprosy colony in Jharia, Dhanbad, Jharkhand. His father, affected by leprosy, struggled to provide for Anil and his three siblings. Leprosy-related stigma and discrimination cause social isolation that added to the family's difficulties.

Anil wanted to pursue a technical degree, but gave up on this ambition for financial reasons. Later, after graduation from secondary school, he found out about the scholarship program, and he was selected for the Bachelor of Education course. He successfully completed the course at Loyola College, Jamshedpur, Jharkhand.

His first job was at Ursuline Convent English Medium School in the neighboring state of Bihar. He taught mathematics to primary school students. His salary allowed him to repay the loan that his father took for his sister's marriage and to renovate his house.

Now at a school in Dhanbad closer to his family, he continues to teach mathematics. To upgrade his teaching qualification, he is simultaneously pursuing a master's degree through a distance learning program.

Anil has become a role model in his colony. He is known to provide counseling whenever any student is confused about their career or which college to choose. He encourages young students to apply for the scholarship supported by S-ILF.

## Rahul Malakar

### Bachelor of Hotel Management and Catering Technology, 2017-2021



Rahul Malakar belongs to Asha Vihar leprosy colony in Dhanbad, Jharkhand. He is the eldest of three siblings. His father, affected by leprosy and with no formal education or professional training, worked in the scrap business for a meager income. Stigma and discrimination affected all members of the family.

Rahul initially aimed to join the Indian Army, but he had to give up on this idea because an accident injured his hand. With no alternative plan, he considered joining the scrap business. After hearing about the scholarship offered through S-ILF, he applied and successfully entered a professional course for the hospitality industry. He achieved second place in his class, which led to an opportunity for a six-month internship at an international chain of hotels in Malaysia. His international career continued as he subsequently worked as a head barista and server at an airport in Oman and then as a steward for a cruise line based in the United States. He currently earns an income in US dollars.

Rahul's father recently had major surgery and can no longer work. Rahul has become the sole income-earning member of his family, and because of his salary, he is able to take care of

all expenses. He is dreaming bigger now, and hopes to open his own hotel chain in the future. He wants more children to have the kind of support that he did so that they can fulfill their dreams as well.

## Expanding coverage

In 2015-16, the first year of the Dalai Lama-Sasakawa Scholarship program, 14 students from three states and one union territory – Bihar, Delhi, Odisha, and Uttar Pradesh – received support. Since then, the program has gradually expanded. For fiscal year 2023, eligible states and union territories included Andhra Pradesh, Bihar, Chhattisgarh, Jharkhand, Madhya Pradesh, Maharashtra, Odisha, Telangana, Uttar Pradesh, and West Bengal. These 10 states and union territories correspond to those identified by India's National Leprosy Eradication Programme (NLEP) as having a prevalence rate per 10,000 population of 0.5 or above. Only Chandigarh and Dadra & Nagar Haveli, with rates of 1.4 and 1.0, respectively, have yet to receive eligibility status.

India's self-settled leprosy colonies exist throughout the country, even in states where the prevalence rate is low. For as long as stigma and discrimination against persons affected by leprosy and their family members persists, S-ILF hopes to expand coverage so that every child can see a path out of isolation and poverty to a professional career.



The Dalai Lama-Sasakawa Scholarship is currently offered to secondary school graduates living in self-settled leprosy colonies in 10 states and one union territory: (in alphabetical order) Andhra Pradesh, Bihar, Chhattisgarh, Delhi, Jharkhand, Madhya Pradesh, Maharashtra, Odisha, Telangana, Uttar Pradesh, and West Bengal (shown on map in light red). "Administrative Map of India with States and Union Territories" by Maximilian Dörrbecker (Chumwa), CC BY-SA 2.5, via Wikimedia Commons at [https://commons.wikimedia.org/wiki/File:India\\_-\\_administrative\\_map.png](https://commons.wikimedia.org/wiki/File:India_-_administrative_map.png) (accessed April 14, 2024), adapted for the *Leprosy Bulletin* by Avinash Gurung.

## WISH LIST



**Evarestus Lilibeth Nwakaego**  
National Coordinator  
Purple Hope Initiative Nigeria (PHIN)

Evarestus Lilibeth Nwakaego is legal practitioner and executive member of the Nigerian Bar Association. She is also a person affected by Hansen's disease and a human rights activist. In addition to her work as PHIN's national coordinator, she contributes at the board and advisory level to numerous Hansen's disease-related initiatives in other organizations.

To stimulate thinking and inspire new approaches, the *Leprosy Bulletin* occasionally asks a person affected by leprosy or an individual involved in leprosy-related work for a list of a few things that they wish could happen.

- 1 I wish that women affected by Hansen's disease could receive technical support to scale up their skills related to food security as this would help them to develop more robust coping mechanisms.
- 2 I wish that persons affected by Hansen's disease, particularly women, could be involved in projects that make them feel committed and independent so that their mental health improves and they have fewer struggles with poverty and stigma.
- 3 I wish that inclusion of persons affected by Hansen's disease in leprosy services at all levels would be properly monitored and implemented.

## SPOTLIGHT

## Purple Hope Initiative Nigeria (PHIN)

Purple Hope Initiative Nigeria (PHIN) is a non-profit, grassroots association of women and children affected by Hansen's disease in the southern part of Nigeria. Its five-person board of trustees comprises four females and one male. Its membership consists of 550 adult women and 72 youth of ages 5 to 20.

PHIN currently operates in five states: Lagos, Abia/Imo, Enugu, Ebonyi, and Anambra. Each state has a chapter with women's self-help and self-care groups headed by its executive members. These groups run weekly, and they are monitored by PHIN's national leadership on a quarterly basis.

PHIN collaborates with RedAid Nigeria, Damien Foundation Belgium, and the Sasakawa Health Foundation.

PHIN's primary activities include advocacy/awareness creation, child education support, social and economic empowerment of women and youth, mental health

counseling, human rights protection, capacity building training, and a revolving loan scheme.



Evarestus Lilibeth Nwakaego, National Coordinator of Purple Hope Initiative Nigeria (PHIN), with some members of the Abia/Imo women's groups at the Vision Africa radio house to create awareness about leprosy and its treatment (Umuahia, Abia State, Feb. 2, 2024).

**SASAKAWA**  
**LEPROSY**  
HANSEN'S DISEASE  
**INITIATIVE**

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