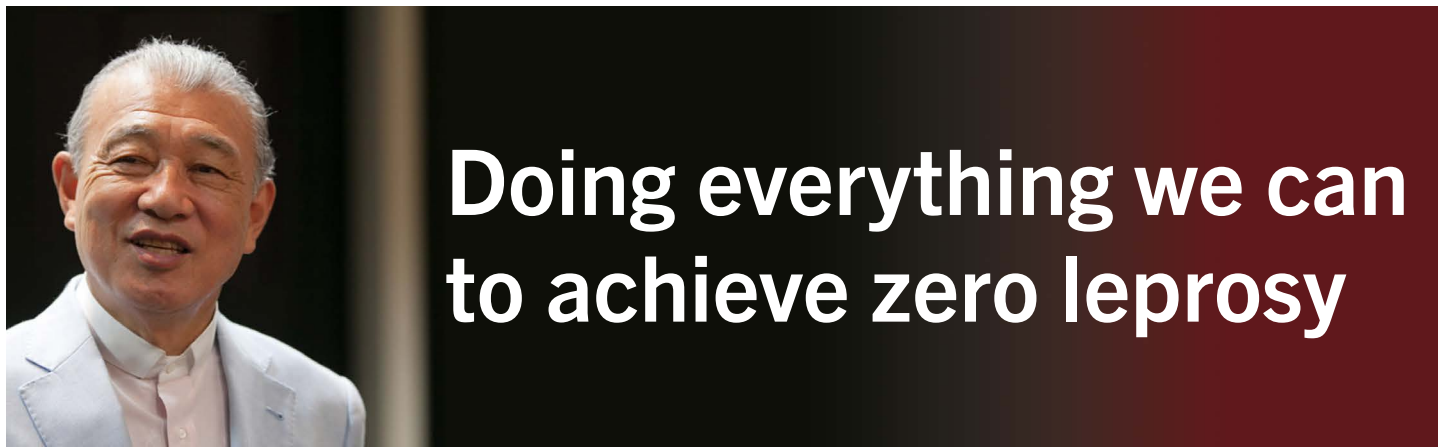


# LEPROSY BULLETIN

NO. 119 FEBRUARY 2024



## Message from the ambassador

In 2006, I initiated the first Global Appeal to end stigma and discrimination against persons affected by leprosy. Since then, the Global Appeal has become an annual event, always scheduled to launch at around the time of World Leprosy Day. This year, the World Health Organization (WHO) hosted the launch ceremony at its headquarters in Geneva, Switzerland. WHO Director-General Dr. Tedros Adhanom Ghebreyesus signed the appeal.

Dr. Tedros reminded attendees of WHO's Global Leprosy Strategy 2021–2030, and stated, "I think all that we need to do is in the strategy. So from my side, representing WHO, I would like to assure Ambassador Sasakawa that we will do everything to support countries to eliminate leprosy by supporting them with the elimination strategy." I felt tremendously encouraged by his words.

After the ceremony, I headed to Tanzania to attempt to climb Mt. Kilimanjaro. I wanted to hold the "Don't Forget Leprosy" banner at the top of Africa's highest peak to raise awareness that persons affected by leprosy and their families are still facing stigma and discrimination and to urge everyone to take action to reach zero leprosy. Six grueling days of walking resulted in a successful summit on Feb. 12, and I raised the banner at 5,685 meters above sea level. I later found out that I set a record for being the oldest person to reach the summit – at age 85 and with a pacemaker in my heart.

Each new action renews my resolve to devote all that is left of my life to achieving zero leprosy. I am counting on every *Leprosy Bulletin* reader to join me in working toward this target.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

**Dr. Bardan Jung Rana**

WHO Representative to Bangladesh

**Ramesh Kumar Choudhary**

Lalgadh Leprosy Hospital & Services Centre (LLHSC)

**Mohan Arikonda**

Association of People Affected by Leprosy (APAL)

**Andrea Victoria Aguilera Paredes**

Miss Supranational 2023

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

# Sasakawa Leprosy (Hansen's Disease) Initiative partners with World Health Organization to launch Global Appeal 2024 in Geneva

The Sasakawa Leprosy (Hansen's Disease) Initiative and the World Health Organization (WHO) partnered to launch this year's Global Appeal to end stigma and discrimination against persons affected by leprosy at WHO headquarters in Geneva, Switzerland. More than 100 people attended the launch ceremony on January 31, 2024, including permanent mission representatives, non-governmental organization (NGO) leaders, and WHO officials.

Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination and Chairman of The Nippon Foundation, initiated the Global Appeal in 2006. Scheduled annually to coincide with World Leprosy Day on the last Sunday in January, the Global Appeal comprises a written appeal (statement of issues and call for action) along with a launch ceremony at which the appeal is read aloud. In order to spread awareness and encourage solidarity, the Initiative seeks a new set of influential individuals and organizations to attend the event and sign the appeal each year. This year, the appeal was signed by WHO Director-General Dr. Tedros Adhanom Ghebreyesus.

The Initiative reached out to WHO because of the organization's influence on national leprosy programs worldwide. During the COVID-19 pandemic, restrictions and diversion of resources disrupted control and prevention activities. Now that the crisis has passed, the time is right to urge countries to revisit WHO's Global Leprosy (Hansen's disease) Strategy 2021-2030 and intensify efforts to reach the targets.

In addition to stating intentions to help countries to rebuild national efforts and ensure better access to care for all, this year's appeal identifies a well-informed public as "our greatest ally in this endeavor." The appeal urges members of the public to educate themselves, encourage treatment seeking, reject discrimination, and spread awareness.

The launch ceremony opened with a special concert featuring Stradivarius violinists Giuseppe Gibboni and Rino Yoshimoto. A series of video messages followed, and then Director-General Dr. Tedros and Goodwill Ambassador Sasakawa took the stage for a dialogue about past collaboration and expectations for the future. The event finished with a reading of the appeal by Anushka Sarna from India and Ahlula Moyo from South Africa, children of WHO staff members based in Geneva.

The video messages began with a call from the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy, Dr. Beatriz Miranda Galarza, for a human-rights-based system of quality care and support. In her words, "Guaranteeing access to a high-quality support and care system is not only a human rights obligation, but also a condition to ensure the elimination of discrimination against persons affected by leprosy and their families."

The Special Rapporteur's statement was followed by messages from persons affected by leprosy in Bangladesh, Brazil, Ethiopia, Ghana, India, Indonesia, and Tanzania. WHO Representatives from four high-burden countries – Bangladesh, India, Indonesia, and Somalia – also contributed messages.

Dr. Bardan Jung Rana, WHO Representative to Bangladesh, highlighted that Prime Minister Sheikh Hasina called for Bangladesh to achieve zero leprosy by 2030 at national leprosy conferences in 2019 and 2023. He expressed his willingness to work with the government and the private sector to realize this goal.

Dr. Roderico H. Ofrin, WHO Representative to India, reported that India's five-year National Strategic Plan and Roadmap for Leprosy, launched in 2023, prioritizes combating stigma and ensuring the protection of the human rights of persons affected by leprosy. A critical component of this plan is to repeal all remaining discriminatory laws at the national and sub-national levels. The plan also includes the provision of psychological care and counseling to promote mental health.

In his dialogue with the Goodwill Ambassador, Dr. Tedros indicated that WHO's Global Leprosy (Hansen's disease) Strategy 2021–2030 clearly sets out what needs to be done to achieve zero leprosy, and he affirmed that WHO will support countries as they implement it. He emphasized that promoting community cooperation and eliminating stigma and discrimination through a people-centered approach will contribute to early diagnosis and prevent disability.

Goodwill Ambassador Sasakawa ended with the observation that next year will mark 50 years of collaboration with WHO to eliminate leprosy. He explained that he feels a sense of responsibility for showing results of the long collaboration, and he reiterated his intention to devote the rest of his life to the cause.



While at WHO headquarters for the Global Appeal, Goodwill Ambassador Sasakawa joined Director-General Dr. Tedros at his periodical press conference. He asked the media to help with spreading correct knowledge about leprosy in order to achieve zero leprosy by 2030.



Dr. Tedros Adhanom Ghebreyesus, WHO Director-General, participates in a dialogue session with Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, at the 2024 Global Appeal launch event in Geneva, Switzerland (Jan. 31, 2024).



Anushka Sarna from India and Ahlula Moyo from South Africa, children of WHO staff members based in Geneva, practice reading the Global Appeal on stage before doing it in front of over 100 invited guests at the launch ceremony.

**Video recordings from Global Appeal 2024**

<https://gasasakawa.org/globalappeal2024/>



## Full text of Global Appeal 2024 to end stigma and discrimination against persons affected by leprosy

Leprosy, a disease with ancient origins, still lingers in our world, primarily affecting countries in Asia, Africa, and South America. While it is now curable, the enduring stigma and discrimination surrounding leprosy remain barriers to its elimination. Early detection and treatment can prevent physical impairment, but fear of discrimination often keeps people from seeking help.

To envision a world without leprosy, we must collectively reject the discrimination that clings to this disease and reach every case. The COVID-19 pandemic made the fight against leprosy harder by disrupting country efforts to control the disease. The World Health Organization, Sasakawa Leprosy (Hansen's Disease) Initiative, and partners are working with countries to help rebuild these national efforts and ensure better access to care for all. Our greatest ally in this endeavor will be a well-informed public.

Here's how you can help:

### Educate Yourself

Learn the facts about leprosy, its curability, and the importance of early treatment and possible prevention.

### Encourage Treatment Seeking

If you come across a suspected case of leprosy, prompt treatment is vital. Treatment is available free of charge. Encourage people to seek help.

### Reject Discrimination

Treat everyone with compassion and respect, regardless of their health status.

### Spread Awareness

Share accurate information about leprosy and challenge stereotypes within your community.

Together, we can create a world where no one is left behind on account of a treatable disease. Let us break the chains of discrimination, work toward a leprosy-free world, and ensure dignity and care for everyone affected by this disease.



## VIEWPOINT



**Dr. Bardan Jung Rana**  
**WHO Representative**  
**World Health Organization Country Office for Bangladesh**

Dr. Bardan is a medical doctor who also completed a master's degree in public health at the National University of Singapore and postgraduate studies in tropical medicine and hygiene at London University. He has been WHO Representative to Bangladesh since December 2017.

## WHO supports Bangladesh's new strategic plan

Leprosy is an ancient neglected tropical disease that still occurs in more than 120 countries across the world. According to the World Health Organization (WHO), 174,087 new cases were detected globally in 2022, corresponding to a detection rate of 21.8 per million population. This represented an increase of 23.8% over the 140,594 new cases detected globally in 2021. The South-East Asia region alone accounts for 71.4% of these new cases, with 70.1% child cases and a child case detection rate of 14 per million child population.

Bangladesh is one of the 23 priority countries with a high burden of leprosy, ranking fifth in the world according to WHO. Almost 3,000 new leprosy cases were detected in the country in 2022.

Bangladesh continues to strive towards achieving elimination of the transmission of leprosy and there have been concerted efforts over the years actively led by the government and supported by partners. The country achieved public health elimination of leprosy in 1998 at the national level and has repealed the 1898 Lepers Act, ensuring there are no discriminatory laws against persons affected by leprosy.

At the 2nd National Leprosy Conference in Dhaka on Nov. 12, 2023, Bangladesh unveiled a new National Strategic Plan for Leprosy 2023-2030, which aims to achieve zero leprosy by 2030. The plan focuses on four strategic pillars: strengthening leprosy services and integration into the general health system; preventing the occurrence and worsening of disabilities by timely detection and effective management of complications; promoting social inclusion and empowerment of people affected by leprosy; and enhancing research, monitoring, and evaluation.

The Government of Bangladesh, in collaboration with WHO, national and international NGOs, and people living with leprosy, has been carrying out various leprosy control activities to achieve the goal of eliminating leprosy transmission by 2030. These leprosy control activities are expected to contribute to the reduction of leprosy burden, the improvement of health outcomes, and the elimination of stigma and discrimination for people living with leprosy in Bangladesh. Some of the leprosy control activities in Bangladesh in 2023 included integrating

leprosy services into the general health system, scaling up preventive chemotherapy with single-dose rifampicin for contacts of leprosy patients, providing comprehensive care for people living with leprosy, enhancing the involvement and participation of people living with leprosy and their organizations in leprosy control activities, improving the monitoring and evaluation of leprosy programs, and advocating for the adoption of anti-discrimination laws.

The Sasakawa Leprosy (Hansen's Disease) Initiative has been supporting this effort by the Government of Bangladesh, funding key activities towards attaining elimination of leprosy transmission. I appreciate this continued support by the Initiative, which has been pivotal in the decline of reported cases over the years, the decrease in stigma and discrimination, and our efforts to eliminate leprosy transmission in Bangladesh.

WHO continues to engage with the National Program and its partners and provides strategic support in developing an integrated, country-owned zero leprosy roadmap; scaling up leprosy prevention alongside integrated active case detection; managing leprosy and its complications and preventing new disability, combating stigma, and ensuring human rights are respected. WHO strives towards supporting the country to achieve zero infection and disease, zero disability, zero stigma and discrimination, and the elimination of leprosy through interruption of transmission. We also recognize that global and national investment is essential to achieve zero leprosy. We appreciate and remain a committed partner of the Sasakawa Leprosy (Hansen's Disease) Initiative in this effort towards attaining the elimination of leprosy transmission in Bangladesh.



WHO provided technical support for the development of a revised National Leprosy Strategy for 2023-2030, which was unveiled by Prime Minister Sheikh Hasina during the 2nd National Leprosy Conference (Dhaka, Bangladesh, Nov. 12, 2023).

## VIEWPOINT



**Ramesh Kumar Choudhary**  
**Manager, Community Health and Development**  
**Nepal Leprosy Trust (NLT)/Lalgadh Leprosy Hospital & Services Centre (LLHSC)**

Ramesh pioneered the establishment of LLHSC's Self-Care Training Centre as well as Nepal's first Self Help Group (SHG). In his current role, he oversees the hospital's community programs, including 115 SHGs and various projects for achieving zero leprosy.

<http://www.nepal-leprosy.com/>

## Cross-border issues: A vital consideration for leprosy elimination programs

When we talk about leprosy, the focus cannot be just within the boundaries of a single country. The disease does not recognize borders, and thus, cooperation and coordination between neighboring countries are essential for effective elimination. Dedicating resources to shared research initiatives and implementing evidence-based strategies across borders can strengthen the drive towards a leprosy-free world.

India and Nepal share open borders, allowing their citizens free transit between the two nations. This freedom is utilized for various purposes including seeking medical treatment. Many Indians, in particular, travel to Nepal for leprosy treatment, primarily at the Nepal Leprosy Trust (NLT)/Lalgadh Leprosy Hospital and Services Centre (LLHSC). Roughly 34% of new leprosy patients diagnosed at LLHSC are Indian, and so are 23% of the hospital's annual in-patient admissions. These patients typically stay for three to six months. All services related to leprosy treatment at the hospital are offered free of charge, irrespective of the patient's race, caste, gender, or nationality.

care, a deep cultural understanding and respect, access to excellent facilities and resources, free and easily accessible care, and a comprehensive treatment plan that emphasizes compassionate care.

Complexity arises from the fact that each country has different healthcare systems, cultural norms, and levels of infrastructure. To effectively address leprosy, these differences have to be bridged, and a harmonized approach needs to be adopted. This requires a high level of cooperation, communication, and mutual understanding between the countries involved. Additionally, inclusive and locally tailored strategies that align with each nation's healthcare framework are vital for the successful elimination of the disease.

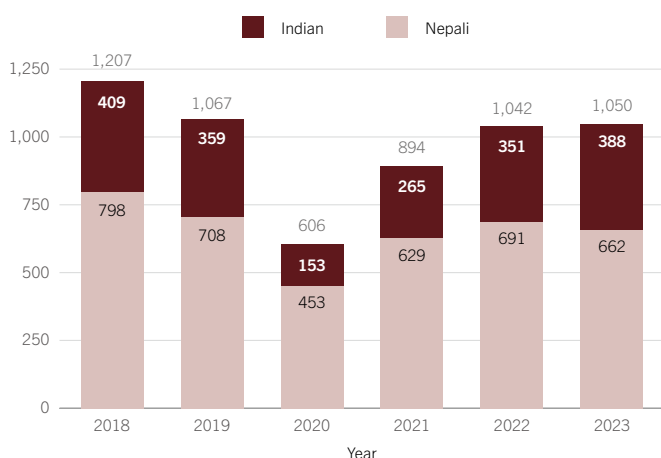
One of the major challenges in cross-border leprosy control is the sharing of information. Different countries may have different reporting mechanisms, making it challenging to have a clear understanding of the actual situation. Unified and standardized reporting systems need to be established to ensure that accurate data is available for effective decision-making and resource allocation.

Stigmatization of leprosy-affected individuals is another critical issue that transcends borders. It is essential for neighboring countries to align their efforts in raising awareness and addressing the social stigma associated with leprosy. This requires collaborative education and advocacy programs that can have a cross-border impact.

Developing a unified strategy for cross-border leprosy control is pivotal. This involves aligning treatment protocols, sharing best practices, and coordinating efforts in contact tracing and surveillance. By working together, neighboring countries can ensure that there are no gaps in the control and elimination of leprosy within their shared regions.

In conclusion, to effectively combat leprosy, countries must work together, transcending boundaries and collaborating for the greater good. Addressing cross-border issues will not only help in the elimination of leprosy but also set a precedent for global health cooperation and solidarity.

**New leprosy patients diagnosed at LLHSC**



Data source: Lalgadh Leprosy Hospital and Services Centre

Many wonder why NLT/LLHSC is such a favored choice for cross-border care. When queried, Indian patients offered several reasons for preferring LLHSC as their treatment center. These include the provision of high-quality specialized

## LETTER



**Mohan Arikonda**  
**Technical Supporting Officer**  
**Association of People Affected by Leprosy (APAL), India**

Mohan started painting in 2016 after completing his leprosy treatment and while searching for livelihood opportunities. He sells his paintings through Atypical Advantage, India's largest livelihood platform for Persons with Disabilities (PWD).

<https://atypicaladvantage.in/search?query=mohan+Arikonda>

## My experience at Purple Fest in Goa, India

I am Mohan Arikonda. I am a person facing the challenges posed by the disease of leprosy. I am delighted to share that I recently had the opportunity to participate in the International Purple Festival held in Goa, Jan. 8–13, 2024, thanks to the generous support of the Sasakawa Leprosy (Hansen's Disease) Initiative.

The International Purple Festival, India's trailblazing inclusive celebration of persons with disabilities, extends a warm invitation to a realm of limitless possibilities. Here, unity takes center stage, and diversity is embraced with open arms. At the heart of the festival lies the esteemed group of 22 Purple Ambassadors, each representing one of the 21 types of disabilities outlined in the Rights of Persons with Disabilities (RPwD) Act, 2016.

During the festival, I participated in the Live Painting and Exhibition event under the distinguished category of Leprosy Cured Persons. It was a profound honor to showcase my artistic skills and deliver my best performance, contributing to the vibrant and enriching atmosphere of the event. The event management team's notable efforts were evident in the well-organized and inclusive interventions, which created opportunities for income generation, provided special care and arrangements, facilitated accessible travel arrangements, and offered instant help through a system of volunteers. I was also impressed by the organizers' commitment to treating all participants and their guardians with equal respect and consideration, which added to the overall positive experience.

I had the privilege of contributing to the Leprosy Convention held on Day 5 of the festival. Supporting organizations included The Leprosy Mission, Sasakawa Leprosy (Hansen's Disease) Initiative, Vidhi Centre for Legal Policy, and the National Centre for Promotion of Employment for Disabled People. During the convention, I expounded to the audience on the significance of the various activities undertaken by APAL in rehabilitating individuals impacted by leprosy and their families, with the aim of restoring their dignity and integrating them back into mainstream society.

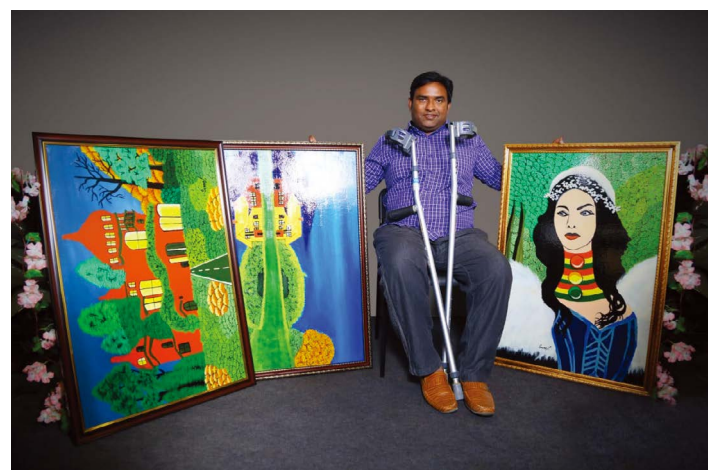
As a person affected by leprosy, my biggest takeaway from my painful experiences is the fear of stigma and discrimination.

This fear can often render individuals affected by the disease apprehensive about their future. It is noteworthy that the term "afraid" has become synonymous with leprosy. The adverse impact of this social stigma is evident in the poor living conditions and lack of livelihood opportunities that affected individuals often face, leading to a sense of despair and loss of confidence. Creating opportunities for sustainable livelihoods and promoting a supportive social environment can facilitate a sense of hope and empowerment among individuals affected by leprosy. I have learned that, despite the challenges, those affected by the disease must remain optimistic and avail themselves of available resources to overcome their predicament.

I extend my sincere gratitude to the Initiative for enabling me to be a part of such a significant platform, one that fosters inclusivity and empowerment for individuals with disabilities.



Mohan Arikonda shows his artwork along with other participants in the Live Painting and Exhibition event at the International Purple Festival held in Goa, India, Jan. 8–13, 2024.



Mohan Arikonda began painting as part of a search for livelihood opportunities.



## LETTER



**Andrea Victoria Aguilera Paredes**  
**Miss Supranational 2023**  
<https://www.instagram.com/andreaaguilerapa/>

Miss Supranational is an international beauty pageant that emphasizes natural grace and community service. Andrea Aguilera, representing Ecuador, won the crown at the 2023 competition. At this same competition, Miss Supranational and the Sasakawa Leprosy (Hansen's Disease) Initiative launched a partnership to raise awareness of Hansen's disease.

## Miss Supranational 2023 visits Iquitos, Peru

I recently had the incredible opportunity to visit Iquitos, Peru, to experience firsthand the work being done there by a phenomenal team. During my visit, I was deeply moved by the resilience and strength of the people I met, particularly Silvia, the leader of the association of persons affected by Hansen's disease in Loreto.

Silvia opened her heart and community to us, sharing the stories of around 70 individuals, each with their own unique experiences. Among them was Juan (name changed for privacy), a man whose bravery and perseverance touched me deeply. Juan shared how he was the only one in his family affected by leprosy, yet he found love, started a family, and his wife and children never contracted the disease. The stories were both heartbreaking and inspiring, highlighting the challenges they face due to their inability to work and the lack of support, even for basic medical needs.

One glaring issue that stood out to me was the absence of psychological care for these individuals. It was evident that something as simple as being listened to and acknowledged meant the world to them. This realization has reinforced my commitment to advocating for their cause and providing support wherever possible.

During our visit, I also had the privilege of meeting Dr. Ramal, a dedicated physician deeply invested in combating Hansen's disease. His ambition to establish a laboratory for further research into the disease underscored the urgent need for greater awareness and resources in this field.

As a recipient and spokesperson for the stories of persons affected by Hansen's disease, I am more determined than ever to work alongside the Sasakawa Leprosy (Hansen's Disease) Initiative and Miss Supranational to address the stigma attached to the disease. Together, we have already made strides in Brazil, and I am eager to continue our efforts to ensure that Hansen's disease is no longer misunderstood or cause for discrimination.

My mission is clear: to eliminate stigmas, provide crucial information for early diagnosis, and ensure that those affected receive the physical and psychological care they deserve, enabling them to fully integrate into society. By amplifying their

voices and advocating for change, we can make a tangible difference in the lives of those affected by Hansen's disease.



In reflecting on her visit to Iquitos, Miss Supranational 2023, Andrea Aguilera, commented, "Now, more than ever, I understand that we should leave no one behind."



Mister Supranational 2021, Varo Vargas, who is from Peru, joined Miss Supranational 2023, Andrea Aguilera, for her visit to Iquitos.



# Kicking off 2024 from Switzerland and Tanzania

In January, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa traveled to WHO headquarters in Geneva, Switzerland, for the annual Global Appeal to end stigma and discrimination against persons affected by leprosy. Soon afterward, in February, he visited Tanzania to raise the “Don’t Forget Leprosy” banner on Mt. Kilimanjaro.

The Global Appeal is sent out every year by the Goodwill Ambassador in partnership with influential organizations and individuals from around the world. This year’s partner was the World Health Organization (WHO). The Goodwill Ambassador and Director-General Dr. Tedros together sent out the message that it is time to reinvigorate efforts that were stalled because of the COVID-19 pandemic and actively pursue zero leprosy.

As covered in the 110th issue of the *Leprosy Bulletin*, the Goodwill Ambassador climbed Japan’s Mt. Fuji in August 2022 to show his commitment to the “Don’t Forget Leprosy”

campaign. The success of the climb as an awareness-raising activity made him wonder about how he could do it again in a place where attention would matter even more. He decided to aim for Mt. Kilimanjaro in Tanzania.

Mt. Kilimanjaro is similar to Mt. Fuji in that it is also volcanic and freestanding, meaning that it is not part of a mountain range. Both mountains can be climbed without technical mountaineering skills. But Mt. Kilimanjaro is not just the highest mountain in Tanzania; it is the highest in all of Africa. Climbing it would be an opportunity to bring attention to leprosy throughout the entire continent.

Battling low oxygen levels and cold temperatures, the Goodwill Ambassador began the final leg of the ascent in the middle of the night. On Feb. 12, 2024, just before dawn, he reached Gilman’s Point (5685 meters), one of Mt. Kilimanjaro’s three summits. Amid rock and snow, he spread the “Don’t Forget Leprosy” banner in a message to the world.



Goodwill Ambassador Sasakawa and Director-General Dr. Tedros reaffirmed their commitment to helping countries achieve zero leprosy.



At the Horombo Hut campsite, a stop along the way down the mountain, guides celebrated with the Goodwill Ambassador.



After six days of walking, Goodwill Ambassador Sasakawa spread the “Don’t Forget Leprosy” banner on Mt. Kilimanjaro’s Gilman’s Point (5685 meters).

**SASAKAWA  
LEPROSY  
HANSEN'S DISEASE  
INITIATIVE**

WHO Goodwill Ambassador's Leprosy Bulletin No.119

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