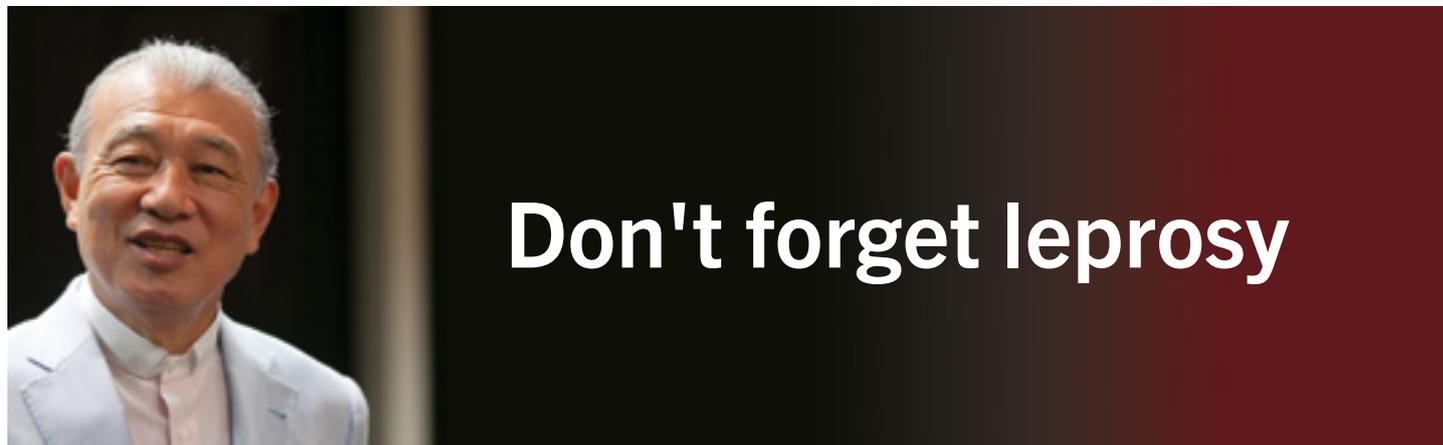


LEPROSY BULLETIN

NO. 104 JULY 2021



Message from the ambassador

This year marks the 20th anniversary of my appointment as the WHO Goodwill Ambassador for Leprosy Elimination. I am using this occasion to launch a 10-month campaign aimed at stakeholders called “Don’t forget leprosy.” For the duration of the campaign, I would like to share some thoughts here about my role and how I have approached it.

My father was a man who devoted his life to the service of others. When he was young, a teenage girl who lived in his neighborhood suddenly disappeared. He later found out that she was forced to leave because of leprosy, and he was angry that something so unjust could happen.

In 1976, I accompanied my father to the opening ceremony for a hospital in South Korea. When we went to visit the patients, their expressionless appearance, without any light in their eyes, surprised me to the point that I just stood there at the doorway. But my father walked right in and engaged naturally, rubbing their bandaged limbs, giving hugs, and speaking encouraging words. In shock, and grasping only that this was a world that I knew nothing about, I decided then that I would make it my life’s mission to follow his example. For 45 years since then, I have been working to reduce patient numbers and to secure human rights for every affected person.

I have three personal philosophies that I use to guide my actions: 1) the place where problems are happening is also where solutions will be found; 2) taking action to transform society requires a strong and committed spirit that can withstand hardships; and 3) I must keep going until results are obtained. Based on these philosophies, I have taken more than 200 trips to nearly 100 countries in order to learn about problems and solutions firsthand.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Dr. Tedros Adhanom Ghebreyesus
Director-General, World Health Organization

Alice Cruz
United Nations Special Rapporteur

Jayashree P. Kunju
Vice Chair, Lepra Society
Member of the Board, IDEA International

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

INTERVIEW



Dr. Tedros Adhanom Ghebreyesus
Director-General
World Health Organization (WHO)

Dr. Tedros's profile on WHO's website:
<https://www.who.int/director-general/biography>
Twitter: @DrTedros

WHO Goodwill Ambassador for Leprosy Elimination's role is to make sure that leprosy is not forgotten

LB (Leprosy Bulletin): Thank you for your time during this crisis period of the COVID-19 pandemic. Please tell us a bit about WHO goodwill ambassadors. What difference has it made to have a goodwill ambassador for leprosy elimination?

Dr. Tedros: WHO goodwill ambassadors are typically distinguished personalities who focus on specific global health issues. They come from various backgrounds and include former heads of state, celebrities from sports or the arts, philanthropists, and other noted individuals.

Goodwill ambassadors can open doors that remain otherwise closed. They get the attention of a variety of people: heads of state or government, political leaders, businesses and entrepreneurs, journalists, donors, and the general public. They can help in raising funds and awareness.

Leprosy is an almost forgotten disease in many countries. We are grateful that Mr. Sasakawa has undertaken visits to numerous countries across the globe. He often meets with kings, presidents, prime ministers, ministers of health, and finance ministers.

But his interactions are not limited to decision-makers. He has always made it a point to meet people affected by leprosy and the communities in which they live.

This has involved travel to remote places and interacting with some of the most disadvantaged groups in society. His visits have been well covered by local and international media as well as through his own bi-monthly newsletter.

As such, his country visits continue to be successful in that he ensures leprosy gets the attention of the highest officials and he is able to share the harsh realities and sufferings (and the happy moments) of people affected by leprosy.

We are all thankful for the contribution he has made to leprosy control programs in many countries. We can now harvest the fruits of his relentless efforts as the leprosy epidemic is slowly but surely fading away globally.



Dr. Tedros with WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa upon the renewal of his appointment (Geneva, 2018).

Influenced by the adage “nothing about us without us,” Mr. Sasakawa has advocated for the inclusion of persons affected by leprosy, particularly in leprosy endemic countries. This has helped to greatly improve the reach and quality of leprosy services.

LB: The coronavirus pandemic has disrupted health services, including leprosy services, as countries prioritize measures against COVID-19. What do you expect of the WHO Goodwill Ambassador for Leprosy Elimination under these circumstances?

Dr. Tedros: COVID-19 has had a major impact on societies and has negatively impacted many programs. Leprosy control is typically a marathon program; not a sprint. By nature, it tends to slip down the list of priorities when a country is hit by an acute, urgent event like a pandemic, natural disaster, or other emergency.

In the context of a temporary setback in leprosy control because of the COVID-19 pandemic, Mr. Sasakawa's

role is as important as ever in making sure that leprosy is not forgotten. The leprosy community can even contribute to addressing emergencies such as COVID-19, by sharing its experience in contact tracing; by opening its hospital infrastructure for acute cases; by addressing mental health needs; and so on. It is also important that he maintains contact with actors in the field — including WHO, national leprosy programs, partners, and affected communities — and that he stays prepared to provide support for leprosy activities when they resume, expand, and ultimately return to their full swing.

LB: The Goodwill Ambassador believes in finding solutions locally and so is keen to resume his visits to leprosy-endemic countries when circumstances permit. Do you have any advice for him concerning his post-pandemic activities?

Dr. Tedros: Following in the footsteps of his late father, Ryoichi Sasakawa, for more than 40 years and having served as WHO Goodwill Ambassador for 20 years, Mr. Sasakawa knows very well what works in what situation. Indeed, homegrown solutions with a firm local stake and fully owned by local governments and communities will always work better than solutions imposed from outside.

COVID-19 has changed the world. The pandemic will recede, but we will not go back to the way things were. Adaptation to the “new normal” will be required. But there are also new opportunities that have come along with COVID-19. These can benefit leprosy control. Digital health has received a major impetus. Virtual meeting platforms enable us to bring people together more than ever before, opening possibilities to train more health workers and provide better coordination and collaboration among partners in the field. Remote diagnosis and patient management have got a boost. Addressing mental health issues is now also much more prominent. All these areas are relevant for leprosy control and WHO would value Mr. Sasakawa's advocacy for expanding the use of these tools.

LB: This year, WHO released a new Neglected Tropical Disease (NTD) roadmap for 2030 as well as a global leprosy strategy for 2021-2030. How optimistic are you that the targets will be met, and how do you see the WHO Goodwill Ambassador contributing to their achievement?

Dr. Tedros: WHO has developed both documents through a broad, consultative process with many stakeholders, including national disease control programs, ministries of health, development partners, donors, affected communities, research bodies, and others. As such, the proposed strategies have been well considered, and although the targets are ambitious, they are realistic. The targets are global, which means some countries will

need to set higher national targets and perform better than the global average, while other countries with weaker health systems may define targets that will contribute to these global targets. Several targets may be only achieved in a best-case scenario. I can, therefore, see a role for Mr. Sasakawa to advocate for the new strategy and for doing everything possible to achieve its targets.

I look forward to Mr. Sasakawa's continued interaction with high-level officials as well as with technical partners to remind them about the scourge of leprosy. We also appreciate his commitment to continue to provide funding that can and should be used in the most strategic way to leverage funding from other sources, and in particular domestic funding, so that necessary leprosy control activities can be implemented in the most efficient, effective, and cost-effective way. It is proven that the right investments in control of NTDs, health systems, and health promotion can yield very high economic returns.

A substantial number of countries report only a few leprosy cases. Provided that control activities are maintained and further strengthened, it is expected that many of these will eliminate leprosy in the coming years. For high-burden countries, a significant reduction in disease burden is a realistic goal. We count on Mr. Sasakawa to amplify WHO's efforts to this effect in all countries.

LB: What lessons must the world learn from the coronavirus pandemic? Can some of these lessons apply to leprosy and other NTDs?

Dr. Tedros: In addition to what I have mentioned earlier, we should not forget that COVID-19 knows no national boundaries. Travel restrictions will gradually be lifted and cross-national interactions will again increase. The world will only be safe if all countries and all communities are safe. Hence, it is imperative that all people are reached with adequate control measures. Furthermore, successful COVID-19 control depends on having the right institutional mechanisms in place, adequate funding, trained health workers and volunteers, diagnostic tests, vaccines, and the determination to succeed.

The same applies to leprosy. Achieving zero leprosy will only be possible if the right services are provided to all who need them. This includes not only diagnosis, treatment, and preventive measures, but also disability care, mental health support, and activities to reduce stigma and discrimination. As with COVID-19 control, adequate human resources must be in place, investments in research must be scaled up, and services expanded in scope and reach.

REPORT



Alice Cruz
United Nations (UN) Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members
<https://www.ohchr.org/EN/Issues/Leprosy/Pages/LeprosyIndex.aspx>
 Twitter: @srleprosy

Born in Portugal, Alice Cruz trained in anthropology and wrote her Ph.D. thesis on national differences in barriers to diagnosis, care, and social inclusion as experienced by persons affected by leprosy. She has held the mandate for UN Special Rapporteur since it was first established by the Human Rights Council in 2017.

Disproportionate impact of COVID-19 pandemic on persons affected by leprosy and their family members

While it is true that there is increased dynamism with regard to the recognition of persons affected by leprosy as rights-holders, as well as greater attention to issues of gender and participation, one cannot deny the substantive setback brought on by the COVID-19 pandemic. The year 2021 began with confirmation of the concerns I had shared with Member States in my open letter on leprosy and COVID-19 issued in mid-2020.¹ Both official and non-official numbers point to around 50% decrease in the diagnosis of new cases; increase in the number of hidden cases; increase in the number of people being diagnosed with irreversible physical impairments as a result of late diagnosis; well-founded concerns over an increase in transmission rates and new cases among children, who may also be more likely to be diagnosed with already irreversible physical impairments.

Such setbacks in diagnosis and transmission are just some of the many adverse effects of the pandemic. Both structural material deprivation and systemic discrimination have been playing a terrible role in menacing and violating the very right to life of the most vulnerable, including persons affected by leprosy and their families. Moreover, another key factor has come to light: the existence of double standards in the responses from varied stakeholders to the current crisis.

Since March 2020, I have been receiving reports from all leprosy-endemic countries about a food emergency among persons affected by leprosy and their families, along with reports on issues of equally great concern impacting their right to life. The COVID-19 pandemic has become one additional basis for discrimination. Persons affected by leprosy, who were already excluded from the formal economy and denied entitlements to social protection, have been facing the loss of income-generating activities and safety nets. Importantly, drugs used for treating leprosy reactions are immunosuppressive, which means that a high percentage of persons affected by leprosy are especially vulnerable to COVID-19, more so in the context of living in vulnerable material conditions without access to basic goods, but

also in lack of access to life-saving information. I have also received many reports pointing to a generalized pattern of multiple barriers to access to healthcare. Access to essential medicines, namely multidrug therapy (MDT), has also been compromised during the pandemic. During the period from mid-2020 to the beginning of 2021, I have received complaints about the shortage of MDT in 10 countries.

Significant improvement in many areas is indispensable with regard to recovery plans. I would like to highlight one area in particular: the need to guarantee the right to participation in pandemic-related plans and recovery to marginalized and discriminated-against groups, because they are frequently invisible and forgotten in national planning and also because community engagement is a well-documented key strategy for responding to outbreaks in an equitable, appropriate, and efficient manner. In my report to the Human Rights Council,² I consider good mitigation practices the ones that were developed through collaborative work with people's organizations, guaranteeing the co-production of health, respecting autonomy, enhancing local capacities, and linking relief to development.

The COVID-19 pandemic has brutally revealed how the principle of universality of human rights as provided for in the Universal Declaration of Human Rights has hardly been fulfilled. But if one thing has become clear during the pandemic, it is that "other people's problems" are everyone's problems. That is why I have recommended to Member States to put those who are furthest behind at the center of an inclusive recovery by eliminating double standards in the response to the current crisis, ensuring non-discrimination and the right to participation for the most marginalized. Minimum core obligations of social and economic rights (like health, work, social protection, and education) should be established as a matter of priority for vulnerable groups. This is the core principle for building back better by placing those who have systematically been pushed furthest behind at the center of an inclusive recovery.

OPINION



Jayashree P. Kunju
Vice Chair, Lepra Society
<https://leprasociety.in>
Member of the Board, IDEA International
<https://www.ideaadvocates.org/international-network.html>

During her final year of study to become a Chartered Accountant, Jayashree P. Kunju contracted leprosy. Today she is a founding partner and CEO of the Bangalore-based company iBAS Consulting. She has not forgotten the stigma attached to leprosy and is committed to eliminating it.

Look to Global Leprosy Champions for ways to improve post-pandemic leprosy services

Epidemics cause severe disruptions to the delivery of national health services, particularly those related to serving the needs of marginalized communities. Leprosy, already classified as a "Neglected Tropical Disease," has been further neglected as the world grapples with the COVID-19 pandemic.

In India, over 3 million people out of a population of 1.3 billion are affected by leprosy. Persons affected by leprosy often live in rural parts of the country where access to diagnosis, treatment, and post-cure care is limited due to geographical isolation and poor access to public health dispensaries or centers. Many individuals do not receive treatment in time to avoid physical impairments and disabilities. Even after being cured, they are still affected by the consequences of the disease.

In preparation for the day when we are done with the pandemic, we need to find innovative and effective ways to develop leprosy services to serve patients living in remote areas with least access to healthcare support. The specific needs of persons affected by leprosy include testing for the disease, psychological counseling, economic rehabilitation, physiotherapy, medication, ulcer care, training in self-care, administration of medicines, active case-finding surveys, and reconstructive surgery.

My background in accounting and business makes me sensitive to the need to generate value from limited resources. India's Accredited Social Health Activist (ASHA) program is an example of a government-supported, low-cost way to augment medical care, but what can be done for non-medical needs? I suggest that we look to the Global Leprosy Champions group, created in September 2018 by Mohan Arikonda. This informal online association of persons affected by leprosy now has over 600 members from 20 countries.

"Champions" indicates persons affected by leprosy who look out for others similarly affected in order to provide peer support and fellowship. Champions also aim to be role models who speak up about discrimination and inspire others.

Because Champions understand the disease and its ramifications, they are ideal candidates for receiving training in delivery of services that do not call for medical qualification. Many Champions have already found ways to support people living in self-settled colonies. As fellow persons affected by leprosy, they are trusted, and so officially involving them in delivery of services has potential to improve mutual understanding among all stakeholders.



Photo courtesy of Sunil Kumar, an active member of Global Leprosy Champions.



Photo courtesy of Mohan Arikonda, founder of Global Leprosy Champions.

¹ https://www.ohchr.org/Documents/Issues/Leprosy/SR_leprosy_Open_letter_22May2020.pdf

² <https://undocs.org/A/HRC/47/29>

Twenty years as the WHO Goodwill Ambassador for Leprosy Elimination

In 2001, Yohei Sasakawa was appointed Special Ambassador to the Global Alliance for Elimination of Leprosy (GAEL). His appointment was continued in 2004 under the new name WHO Goodwill Ambassador for Leprosy Elimination. Since then, he has been working to realize a leprosy-free world from both a medical and social perspective. He likens this to a motorcycle: just as the front and rear wheels of a motorcycle need to turn

together for progress to be made, so efforts to eliminate the disease and end discrimination must happen in tandem. For 20 years, Sasakawa has been fulfilling his role by making visits to endemic areas to see local conditions; meeting with leaders and health ministers; connecting stakeholders; raising awareness; advocating for human rights; and supporting the self-advocacy of persons affected by leprosy.

Visiting endemic areas



Visit to endemic area in Mozambique (2006). Since his appointment, the Goodwill Ambassador has made over 200 visits to 100 countries.

Meeting with leaders



With Manmohan Singh, prime minister of India (2005). Since his appointment, the Goodwill Ambassador has met with 591 leaders around the world.

Connecting stakeholders



With Meles Zenawi, prime minister of Ethiopia, and Birke Nigatu, a representative of Ethiopian National Association of Persons Affected by Leprosy (2006).

Raising awareness



Press conference in Fiji (2015). The Goodwill Ambassador raises awareness about the importance of leprosy-related issues through a wide range of media.

Advocating for rights



Speech at the United Nations Commission on Human Rights (2004). The Goodwill Ambassador continues to emphasize that leprosy is a human rights issue.

Supporting self-advocacy



At the first Global Forum of People's Organizations on Hansen's Disease, held in the Philippines (2019). The Goodwill Ambassador believes that persons affected by leprosy should have leading roles in the fight against leprosy.

2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021



With Dr. Bertrand Ramcharan, UN Deputy High Commissioner for Human Rights (2003).



At the second National Conference on Integration & Empowerment of People Affected by Leprosy (2005). The Goodwill Ambassador initiated the establishment in India of the National Forum of People Affected by Leprosy, later renamed Association of Persons Affected by Leprosy (APAL).



The Goodwill Ambassador's efforts contributed to the adoption of the "Resolution on the elimination of discrimination against persons affected by leprosy and their families" and the accompanying "Principles and guidelines" (2010).



With Brazil's Deputy Minister of Health (current Assistant Director of PAHO), Dr. Jarbas Barbosa da Silva Jr. (2014). At the World Health Assembly, the Goodwill Ambassador meets annually with health ministers from countries where leprosy is endemic and advocates for strengthening control measures.



With persons affected by leprosy after an international conference in Vatican City organized in collaboration with the Pontifical Council for Health Care Workers (2016). The Roman Catholic Church is one of the largest non-governmental providers of health care services in the world.



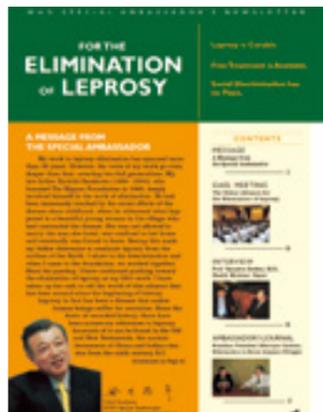
At a Radio Republik Indonesia (RRI) studio to answer phone-in questions about leprosy (2018). Questions included: "What country did leprosy originate in?" and "What should I do if I'm diagnosed with leprosy?"



With Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members (2018). The mandate for the Special Rapporteur was established by the Human Rights Council in 2017 with the strong support of the Goodwill Ambassador.



With Prime Minister Sheikh Hasina of Bangladesh at a national conference held in Dhaka (2019). The prime minister called on the 600 stakeholders in attendance to achieve zero leprosy throughout the country by 2030.



First issue of the WHO Goodwill Ambassador's bi-monthly newsletter (2003). Relunched as the *Leprosy Bulletin* in December 2020.



Founding members of Sasakawa India Leprosy Foundation (S-ILF) (2006). The Goodwill Ambassador co-founded S-ILF with the vision that it would work collaboratively with APAL for the social and economic rehabilitation of persons affected by leprosy.



International Leprosy Summit in Bangkok, Thailand (2013). Health ministers and leprosy program managers from 17 countries that report over 1,000 new cases per year were invited in order to secure their commitment to tackling the disease and break stagnation in leprosy control efforts.



Symposium on Leprosy and Human Rights held in Geneva, Switzerland (2015). The last of five regional symposiums organized by the Goodwill Ambassador to spread awareness of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.



Talking with a person affected by leprosy in Indonesia (2016). The Goodwill Ambassador values hearing firsthand about what is happening at the local level.



Checking multidrug therapy (MDT) supplies at a hospital in Anjouan (2018). Following this visit, WHO and The Nippon Foundation supported the Comoros government in a campaign that increased screening for leprosy and doubled the number of detected cases.



At the 14th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy (2019). Launched by the Goodwill Ambassador in 2006, the annual event is timed to coincide with World Leprosy Day.



With travel restricted during the COVID-19 pandemic, the Goodwill Ambassador increased his use of online tools for communication. Through a new website as part of the Sasakawa Leprosy (Hansen's Disease) Initiative, webinar series, video recordings, and online conferences, he is continuing to spread messages for leprosy elimination.

INITIATIVE NEWS

“Don't forget leprosy” awareness campaign

The Sasakawa Leprosy (Hansen's Disease) Initiative is leveraging the 20th anniversary of the appointment of the WHO Goodwill Ambassador for Leprosy Elimination to launch a 10-month-long awareness campaign called "Don't forget leprosy."

During the 20 years that Yohei Sasakawa has served in the goodwill ambassador role, significant progress toward the elimination of leprosy has been made. Thanks to the combined efforts of many stakeholders — including the World Health Organization (WHO), national governments, non-governmental organizations (NGOs), people's organizations, and various experts — most countries have achieved elimination of leprosy as a public health problem (less than 1 case per 10,000 population). In 2010, the United Nations (UN) General Assembly unanimously adopted a resolution on the elimination of discrimination against persons affected by leprosy, and this resolution was followed by the appointment of the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.

The number of new cases of leprosy worldwide, however, has remained almost unchanged for the past 10 years, and there are still hotspots in many parts of the world. Recently, progress toward zero leprosy has been set back by demands on governments to respond to the COVID-19 pandemic.

“Don't forget leprosy” activities will include a series of six webinars; media briefings held online; dissemination of messages via television and radio; a series of videos featuring the WHO Goodwill Ambassador's activities and messages; and the annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy scheduled for the end of January 2022. The WHO Goodwill Ambassador will take the lead in reaching out to stakeholders, including policymakers, to ensure that leprosy is not forgotten.

UPCOMING EVENTS

Webinar series: Don't forget leprosy

As part of the Sasakawa Leprosy (Hansen Disease) Initiative's “Don't forget leprosy” campaign, a six-part webinar series will kick off in August 2021. The webinars are free of charge and open to all. For details, visit the link below.

1	Introducing the “Don't forget leprosy” campaign	August 2021
2	Leprosy as a human rights issue	September 2021
3	Elimination of leprosy in the world	November 2021
4	Raising awareness about leprosy	January 2022
5	Elimination of leprosy: Initiatives in Asia	March 2022
6	Elimination of leprosy: Initiatives in the Americas and Africa	May 2022



<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/1062/>



**SASAKAWA
LEPROSY**
HANSEN'S DISEASE
INITIATIVE

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