

LEPROSY BULLETIN

NO. 105 SEPTEMBER 2021



Message from the ambassador

As part of the “Don’t forget leprosy” campaign, I am sharing reflections on my role and how I have approached it. For this issue, I would like to explain how a focus on human rights became an important part of my efforts.

As I traveled around the world as a goodwill ambassador, I began to wonder why persons who experienced leprosy (or Hansen’s disease) were still identified with the disease after being cured. They remained “affected” for the rest of their lives. The continuity of stigma and discrimination even after a person was free of the disease indicated to me that medical treatment would not be enough to ensure inclusion in society. I realized that leprosy has a social aspect and should be viewed as a human rights issue. In 2003, I began lobbying the Office of the United Nations High Commissioner for Human Rights.

Until I raised the issue, leprosy-related discrimination had never been discussed within the United Nations Commission on Human Rights. I obtained the first opportunity to speak about leprosy at a Commission session in 2004. Six years later, in 2010, the UN General Assembly unanimously adopted a resolution to eliminate discrimination against persons affected by leprosy and their family members. This resolution gave official recognition to leprosy as a human rights issue. To see this result happen after years of perseverance moved me deeply.

Despite the resolution and the progress that came afterward, there is still a steep path ahead of us. In line with the current SDGs slogan “Leave No One Behind,” I am aiming for inclusive societies where a person who contracts leprosy can be treated, cured, and move on.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

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

INTERVIEW



Michelle Bachelet
 United Nations High Commissioner for Human Rights
 Office of the High Commissioner for Human Rights (OHCHR)

Ms. Bachelet's profile on OHCHR's website:
<https://www.ohchr.org/en/aboutus/pages/highcommissioner.aspx>

Twitter: @mbachelet

We need policies that uphold human dignity

LB (*Leprosy Bulletin*): In the speech you contributed for the launch of this year's Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, you stated that "leprosy remains a neglected and stigmatized disease." What do you think can be done to change this?

MB (Michelle Bachelet): **First, we need more awareness and understanding of the impact that stigma and discrimination have on the dignity and rights of persons affected by leprosy and their family members.**

Furthermore, we need to empower persons affected by leprosy as rights-holders and agents of change. Ensuring their meaningful participation in the design and delivery of programs and services, particularly in leprosy-endemic countries, is critical to sustainability of impact. Making their voices count in policy decisions that affect their lives is key to the realization of a full range of human rights.

We also need to ensure that persons affected by leprosy can access effective mechanisms for remedy and accountability when their rights are violated. Here the justice system and independent national human rights institutions play a critical role, and therefore judges and lawyers need to have a better awareness and understanding of the specific challenges faced by persons affected by leprosy and their family members.

Lastly, we need to continue our efforts to keep zero leprosy high on the national and international agenda.

LB: Mr. Sasakawa has drawn parallels with the discrimination that persons affected by leprosy face and the discrimination experienced by COVID-19 patients, their families, and medical professionals treating them. Why does such discrimination happen, and what can be done to prevent it?

MB: The COVID-19 pandemic has shown us again the weakness of our society and of humanity: fear. The fear generated by myths and misconceptions about communicable diseases has fueled the social stigma and discriminatory behavior. In today's digital society, fear and misconceptions are spreading even faster. To fight against COVID-19 discrimination, there is much we can learn from

the experiences of those who have worked to eliminate stigma attached to leprosy.

We need policies that uphold human dignity and that deliver universal and equal access to social welfare protections and health care, without any form of discrimination. We need to upgrade the quality of health care that has been undermined by austerity measures. We need to invest in education systems and work to advance the right to social protection for everyone. The COVID-19 pandemic has also shown the need for greater solidarity among States and people of all generations. To end stigma and discrimination, we need to make this "our problem," not "theirs." We all need to do our part by upholding human rights and dignity for everyone, and particularly those who suffer from stigma and discrimination because of disease or other grounds.

LB: The coronavirus pandemic has had a disproportionate impact on poor and marginalized communities, among them persons affected by leprosy. What has the past year-and-a-half taught us about human rights?

MB: Rarely has the world faced such a cascade of human rights setbacks and threats as in the past year-and-a-half with the COVID-19 pandemic. It has been shocking to see the disproportionate toll of COVID-19 on individuals and groups who are marginalized and suffer discrimination, including persons affected by leprosy and their family members.

Building back better from COVID-19 is offering us a turning point: a generational opportunity to depart from models that have generated inequalities and fragility and steer our world towards a more inclusive and sustainable society.

We need a life-changing vision — and concerted action — for a human rights economy; human rights-based development; and societies that, in all their diversity, share bedrock commitments to reduce inequalities and advance all human rights for all, leaving no one behind.

For the complete interview, visit
<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/1173/>



REPORT



Geoff Warne
Chief Executive Officer
International Federation of Anti-Leprosy Associations (ILEP)

ILEP is a consortium of non-governmental organizations spanning more than 60 countries that work together to realize a world free from leprosy.
<https://ilepfederation.org>

Eliminating discriminatory laws

One of ILEP's key goals is to reduce to zero the number of countries with legislation allowing discrimination on the basis of leprosy. ILEP's database of discriminatory laws¹ lists details of all known laws that still exist and discriminate against persons affected by leprosy and their family members. Additionally, ILEP and its member associations are at the forefront of lobbying for change, working at various levels, both within countries and internationally, to advocate for the abolition of discriminatory laws and encourage a rights-based and inclusive approach to leprosy.

The ILEP database is a useful resource for countries and organizations interested in advocating for the rights of persons affected by leprosy. The initial research, conducted in 2016, identified discriminatory legislation by analyzing information from several sources, including responses to the Human Rights Council Advisory Committee questionnaire on implementation of the UN Principles and Guidelines; reports and working papers prepared by/for the Advisory Committee; the Law Commission of India report on eliminating discrimination against persons affected by leprosy; ongoing projects and initiatives within ILEP; Internet databases; and published case studies.

Since then, the database is regularly reviewed and promptly updated as new information becomes available from ILEP country representatives, National Leprosy Programme Managers, the WHO global leprosy update, and other sources. The annual review process serves as a prompt, reminding people to act against these laws.

As of August 2021, the ILEP database includes 130 discriminatory laws grouped under six themes: segregation/separation (77); employment (25); immigration (10); marriage/divorce (7); voting (6); and public transport (5). Most of these laws (100) were identified in India. The others are distributed across the rest of Asia (16); Americas (7); Africa (5); Europe and Oceania (1 each). Some laws are a result of the unjust policies of segregation that were implemented in the past and others are more recent; all are offensive and need to be repealed or amended. It is important to note that the database only contains officially published

legislation and does not include any informal practices or regulations that discriminate against persons affected by leprosy and their family members.

With regards to India, successful advocacy and lobbying by ILEP and its members has led to the repeal or amendment of 20 discriminatory laws since 2018. ILEP member The Leprosy Mission has taken the lead through its efforts for policy-based interventions. These include its contribution to the development of The Rights of Persons with Disabilities Act, 2016; a model draft legislation Eliminating Discrimination against Persons Affected by Leprosy (EDPAL) Bill, 2015; and The Rights of Persons Affected by Leprosy and Members of their Family (Protection against Discrimination and Guarantee of Social Welfare) Bill, 2017.

At the international level, ILEP actively supports the mandate and advocacy efforts of the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. Additionally, through its statements, submissions, and briefings² to the UN Convention on the Rights of Persons with Disabilities (CRPD) Committee, the UN Convention for the Elimination of all forms of Discrimination Against Women (CEDAW) Committee, and the Universal Periodic Review process of the Human Rights Council, ILEP continuously highlights the existence of discriminatory laws and calls for their repeal. Recently, The Leprosy Mission and Effect Hope (The Leprosy Mission Canada) have co-organized a petition calling for the repeal of all remaining discriminatory laws.³ This will be presented to the Human Rights Council in September, coinciding with the report by the Special Rapporteur to the UN General Assembly.

ILEP and its members recognize that tackling discrimination goes far beyond the need to repeal or amend discriminatory laws, as they are simply a visible representation of the daily injustices experienced by persons affected in their communities. Through ongoing research, local and international advocacy, and community-based programs, we also work towards ensuring the rights of persons affected and their family members, promoting their inclusion, and reducing all forms of leprosy-related stigma and exclusion.

¹ <https://ilepfederation.org/discriminatory-laws/>

² <https://ilepfederation.org/statements-submissions-and-briefings/>

³ <https://www.thepetitionsite.com/takeaction/670/167/169/?src=LMNZQ21215>



Aarti Thakur
Program Manager (Consultant)
Disabled Peoples' International (DPI)

DPI is a cross-disability international non-governmental organization aiming for full participation of all persons with disabilities in the mainstream of life.

<https://www.disabledpeoplesinternational.org/>

Disability and human rights

According to the World Report on Disability (2011), an estimated one billion people, or 15% of the world's population, experience some form of disability. Moreover, this number is rising because of medical advancements, rapidly aging population, spread of chronic diseases, and conflict and disaster situations. In fact, the United Nations has referred to persons with disabilities as the world's largest minority group.

Unfortunately, persons with disabilities experience stigma and discrimination, including barriers to education, employment, public spaces, housing, transportation, ICTs, aids and appliances, sanitation and healthcare facilities, etc., that are significantly higher than those encountered by non-disabled persons in the same situation. Further, stereotypical views of disability do not consider the diversity of disabilities and intersectionalities that compound these challenges. With an estimated 80% of the world's disabled population living in developing countries, we cannot ignore that poverty, disability, and social exclusion are linked. In many low- and middle-income countries, lack of relevant social protection policies and legal frameworks, segregating institutionalization, and deep-rooted social and religious beliefs play a role in perpetuating negative stereotypes, stigma, and discrimination.

Over time, conceptualization of disability has also been changing, and it is possible to identify four models:

- 1) a **charity model** that views persons with disabilities as helpless and dependent on society;
- 2) a **medical model** that views disability as a disease/impairment within the individual requiring medical intervention;
- 3) a **social model** that views disability as a socially constructed phenomenon and focuses on identifying aspects of an individual's environment (physical, systemic, attitudinal, and social) that have a disabling effect on the individual; and
- 4) a **rights-based model** that views persons with disabilities as rights-holders and equal participants in society.

While the charity and medical models of disability result in further isolation and exclusion of persons with disabilities, the social model initiates a paradigm shift by focusing on reducing/removing barriers that society creates for the full participation of persons with disabilities. Building on the social model, the rights-based model provides an even more dramatic shift in perspective by starting the conversation about empowering persons with disabilities to know and claim their rights and by putting the onus on the State for respecting, protecting, and fulfilling those rights.

An important step in line with this rights-based approach has been the adoption in 2006 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which has 164 signatories and 184 ratifications to date. Unfortunately, despite some progress, few countries are fully compliant, while some countries continue to uphold discriminatory laws and provisions that contradict the articles of the CRPD. For example, mental health laws that allow instances where persons may be detained on grounds of their actual or perceived impairment or provisions disqualifying persons affected by leprosy from standing for elections and holding office conflict with Article 14 (Liberty and security of person) and Article 29 (Participation in political and public life), respectively.

Governments and humanitarian actors have often failed to consider the needs and lived experiences of persons with disabilities in national and international development. Nevertheless, the 2030 Agenda for Sustainable Development has been successful in including persons with disabilities as equal partners in the development agenda. With the current COVID-19 pandemic exacerbating pre-existing inequalities as well as introducing additional challenges — such as communication barriers faced in using tactile signing for Deaf-Blind people due to social distancing protocols — inclusion in development initiatives has become more important than ever. Thus, while we are working towards “Building Back Better” with the pledge to “Leave No One Behind,” there is an emergent need to put persons with disabilities at the center of all development. Only by promoting, defending, and reinforcing human rights of all persons with disabilities can we ensure and secure an inclusive, safe, and sustainable future for all!

LETTER



Tesfaye Tadesse
Managing Director
Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)

Established in 1996, ENAPAL is a community-based organization with over 20,000 members dedicated to securing full participation and equal opportunity for persons affected by leprosy in Ethiopia.

<https://www.enapal.org>

ENAPAL's work on human rights issues in Ethiopia

Warm greetings from Ethiopia. I hope you, your family, and friends are all well.

Ethiopia is located in the northeast of Africa and is known for its coffee beans and some of the oldest human fossils in the world. Most of the country is highland, with the capital, Addis Ababa, reaching an altitude of around 2,400 meters. As a result, there are many world-class track-and-field athletes, some of whom won gold, silver, and bronze medals in the Tokyo Olympic Games this year.

Ethiopia is also one of the countries in Africa where leprosy is ancient and widespread. In 2000, Ethiopia achieved elimination of leprosy at the national level. Despite this achievement, however, more than 3,000 new cases continue to be reported annually. With over 3,200 cases in 2019, Ethiopia had the sixth highest case total in the world and the highest in Africa. In addition, although discriminatory laws have been abolished, stigma and discrimination persist. Persons affected by leprosy and their family members continue to experience social and economic marginalization and exclusion, resulting in the perpetuation of extreme hardships. Sadly, we are now seeing parallels in the discrimination toward COVID-19 patients and their family members. It is a great pity that the awareness of the community regresses or remains stagnant.

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) has been working on human rights issues since the organization's establishment in 1996. For example, we brought a case to the Ethiopian Human Rights Commission (EHRC) and concerned government bodies. It was a clear case of discrimination, but our explanations were not enough. To obtain the kind of proof that they required, we initiated a legal investigation in cooperation with the Bureaus of Labour and Social Affairs and the Justice Department, and we submitted the results to EHRC and the court. However, we found that although many of the discriminatory laws had changed, criminal law still allowed for some stigmatizing and discriminatory practices. Realizing that more work needed to be done in order to achieve permanent structural change, we began working with the legal wing of the Federation of Ethiopian National Associations of Persons with Disabilities

to lobby the government for a provision that addresses legal and customary discrimination against persons with disability. It's hard and steady work, but I think it's very important for making a difference.

In the face of ongoing stigma and discrimination, persons affected by leprosy in Ethiopia are living strong, and ENAPAL's more than 20,000 members are working together to spread correct information about leprosy. ENAPAL has been raising awareness of World Leprosy Day for more than 20 years, and we believe that our steady, grassroots efforts are slowly making a difference in our communities.



Observing World Leprosy Day in Dessie, Amhara Region, Ethiopia (January 2021).

ENAPAL will continue to work with members across the country to tackle stigma and discrimination, and we will continue to work with legal experts to investigate human rights issues. Proper implementation of the Principles and Guidelines depends on these issues being brought to the attention of ombudsmen and the EHRC.

In addition to the COVID-19 pandemic, Ethiopia has been challenged this year by political instability due to national elections and internal conflict. In this context, I believe it is important to continue to work on human rights issues so that leprosy and its human rights implications are not forgotten.

I look forward to seeing you all again in person. Until then, we wish you all the best.

OPINION



Tatsuya Tanami
 Special Adviser (former Executive Director)
 The Nippon Foundation
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Leprosy and human rights in the context of COVID-19

As the novel coronavirus has swept around the world, it has become clear that the disease it causes, COVID-19, bears some similarities to leprosy in the way that it can lead to stigma and discrimination.

At the root of such discrimination is the fear that those infected with the virus or those around them who are at risk of infection will spread the disease to others. Reports of COVID patients and their families — and even medical personnel treating COVID cases — being stigmatized strike a chord with anyone familiar with leprosy.

How to address this kind of discrimination? For leprosy, we have UN Principles and Guidelines (“P&G”). Although the UN P&G are not well known outside leprosy circles, I believe they can serve as a model with wider application.

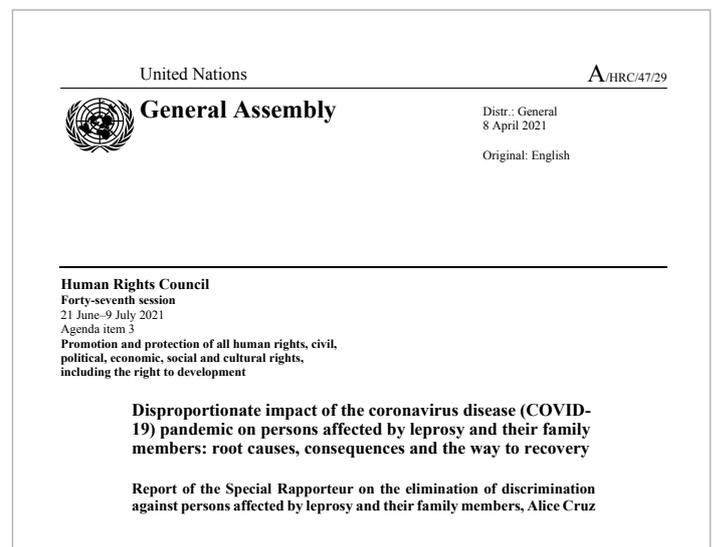
It was Yohei Sasakawa, in his role as WHO Goodwill Ambassador for Leprosy Elimination, who acted to involve the UN after he came to recognize that discrimination in leprosy was a huge yet overlooked social problem. Seven years of advocacy, frequent visits to Geneva, and the cooperation of other stakeholders eventually led to a historic UN General Assembly resolution in December 2010 that endorsed the P&G on eliminating discrimination against persons affected by leprosy and their family members.

Because the P&G are non-binding, getting them to occupy a position high up on a government’s agenda is a challenge. But the UN Human Rights Council’s decision to appoint a UN Special Rapporteur on leprosy in 2017 has ensured that they cannot be filed away and forgotten.

While the COVID-19 pandemic has made it difficult to visit endemic countries, Alice Cruz, the Special Rapporteur, has been working tirelessly to contact governments, international organizations, NGOs, organizations of persons affected by leprosy and individuals with experience of the disease to investigate the degree to which the P&G are being implemented.

What is particularly worrying from a leprosy perspective, as Ms. Cruz pointed out in one of her recent reports, is that health authorities are prioritizing measures against COVID-19 and detection, treatment and follow-up of leprosy patients are

being neglected. There is a real concern that interruption in case detection will result in hidden cases and that delays in diagnosis and treatment will lead to more cases of disability. If that’s the situation, then the discrimination faced by people affected by leprosy will only increase.



Special Rapporteur Alice Cruz’s report to the Human Rights Council about the disproportionate impact of the COVID-19 pandemic on persons affected by leprosy and their family members: A/HRC/47/29 (8 April 2021), available from <https://undocs.org/en/A/HRC/47/29>.

No one should face discrimination on the basis of a disease. Principle 1 of the P&G states: “Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights.” Principle 2 states: “Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.”

We must do everything to ensure that efforts against leprosy and related discrimination are not set back by the coronavirus. The 10-month “Don’t forget leprosy” campaign initiated by the Goodwill Ambassador is helping to keep attention on the need for adequate resources and personnel. Raising awareness of the P&G matters more than ever as we see familiar patterns of stigma and discrimination developing in response to COVID-19. Much is at stake.

Quick reference guide: Principles and Guidelines

In 2008, Japan prepared a draft resolution on the elimination of discrimination against persons affected by leprosy and their family members to be submitted to the UN Human Rights Council. Following the resolution's adoption, the Advisory Committee formulated a draft set of principles and guidelines.

In 2010, a resolution encouraging governments and relevant actors in society to give due consideration to the principles and guidelines was unanimously adopted at the 65th session of the UN General Assembly.

The **Principles** assert that persons affected by leprosy and their family members are entitled to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights and other relevant international human rights instruments.

The **Guidelines** describe how States should promote, protect and ensure the full realization of these human rights and fundamental freedoms without discrimination on the grounds of leprosy. The list below is an unofficial abbreviated version.

1	Promote, protect, and ensure the full realization of human rights and fundamental freedoms for persons affected by leprosy and their family members.
2	Recognize that all persons are equal before the law and entitled to equal protection of the law.
3	Pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups.
4	Support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy.
5	Promote enjoyment of rights, including choice of place of residence, allowing full inclusion and participation in the community.
6	Ensure that persons affected by leprosy and their family members enjoy rights related to participation in political life.
7	Encourage and support employment.
8	Promote equal access to education.
9	Remove discriminatory language from governmental publications.
10	Promote equal access to public places, public transport, cultural and recreational facilities, and places of worship.
11	Provide free or affordable health care to persons affected by leprosy that includes early detection, prompt treatment, counselling, and access to free medication.
12	Recognize the right to an adequate standard of living and provide assistance to persons living in poverty.
13	Raise awareness and foster respect for the rights and dignity of persons affected by leprosy and their family members.
14	Create a committee of stakeholders to develop, implement, and follow up on activities relating to the human rights of persons affected by leprosy and their family members.



ANNOUNCEMENT

Tribute to Dr. S.K. Noordeen (1933-2021)

The *Leprosy Bulletin* is saddened to announce the passing of Dr. S.K. Noordeen, a global leader in the fight against leprosy and a cherished friend. We are grateful to Dr. Derek Lobo for writing this tribute.



Dr. Noordeen at a board of directors meeting for Sasakawa-India Leprosy Foundation (S-ILF) in 2015.

In the passing away of Dr. Noordeen, the cause of leprosy has suffered a blow. Personally, I was blessed to have worked under his able leadership from 1993 until the time of his retirement from the World Health Organization (WHO) in 1998. I continued to benefit from his guidance and friendship afterward as well.

For many years, starting from when he was assigned to WHO's headquarters in Switzerland in 1979, Dr. Noordeen was the main architect of WHO's strategies for leprosy elimination. He worked closely with Sasakawa Health Foundation's medical director, Dr. Yo Yuasa, to develop multidrug therapy (MDT) into an accessible, practical treatment that could be implemented worldwide. Of his many achievements, here I will highlight three:

1. He persuaded National Programmes to integrate leprosy services into General Health Services. In spite of some resistance, he boldly persisted. In India, MDT was made available in 163,000 health facilities under the Health Department.
2. He was the brain behind the 1991 World Health Assembly Resolution that aimed at Elimination of Leprosy as a Public Health Problem (reducing prevalence at the national level to less than one case per 10,000 population by the year 2000). This

numerical target resulted in an increase of political commitment and funding for leprosy work, along with vigorous MDT implementation. By 2000, 114 of 122 endemic countries had achieved the goal. Several more countries, including India, achieved the goal by 2005.

3. Realizing that the main problem affecting MDT implementation was drug supply, he approached The Nippon Foundation (TNF) and its chairman, Mr. Yohei Sasakawa, for support. An arrangement was made for TNF to sponsor free MDT through WHO for all endemic countries 1995-1999. This unprecedented collaboration became a model for provision of global "drug security" for communicable diseases. WHO later used it for filariasis and tuberculosis, and in 2000, the pharmaceutical company Novartis took over the sponsorship role for MDT.

Post retirement, Dr. Noordeen served as the chairman of the Sasakawa-India Leprosy Foundation from the time of its founding in 2006 until 2016 and the president of the International Leprosy Association.

The best tribute we can pay Dr. Noordeen is by working towards a "World Without Leprosy," one of his unfulfilled dreams!



Dr. Derek Lobo

Dr. Lobo has dedicated his life to eliminating leprosy and other poverty-related diseases. For six years, 2001-2007, he worked for the WHO Regional Office for South-East Asia (SEARO) as the Regional Adviser for Leprosy, Filariasis, Soil Transmitted Helminths and Yaws. He is a trustee of the Sasakawa-India Leprosy Foundation (S-ILF) and continues to work as a public health consultant.

**SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE**

WHO Goodwill Ambassador's Leprosy Bulletin No.105

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The *Leprosy Bulletin's* content is posted online at
[https://sasakawaleprosyinitiative.org/latest-updates/
initiative-news/](https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/)



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