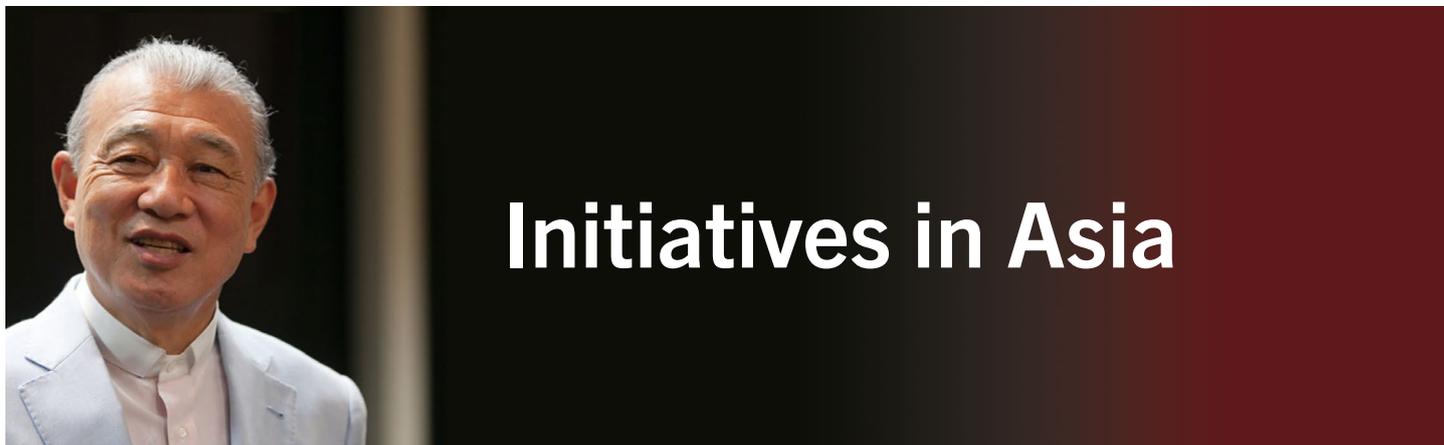


LEPROSY BULLETIN

NO. 108 MARCH 2022



Message from the ambassador

Leprosy, also known as Hansen's disease, is an ancient infectious disease that has challenged humanity across all national, philosophical, racial, and religious borders. With the universality of leprosy's challenges in mind, I visited the United Nations Commission on Human Rights in Geneva for the first of many times in 2003, calling for the elimination of discrimination against persons affected by leprosy and their families. These efforts culminated in 2010 with a UN General Assembly resolution and a related set of principles and guidelines indicating actions that should be taken.

When I visited various colonies in India with representatives from the Association of People Affected by Leprosy (APAL) to explain the resolution, an elderly man raised his hand and said, "I have been subjected to severe discrimination and never once was I recognized as a human being. Do people like me really have human rights?" Experiences like this convinced me that I must fight for a world where no one doubts that they have human rights.

In recent years, the number of people's organizations has been increasing and existing organizations have been strengthening. Even in the context of the COVID-19 pandemic, these organizations are actively working to spread correct knowledge and eradicate prejudice and discrimination.

I am confident that persons affected by leprosy will continue to be actively involved in the fight against leprosy in their respective countries and their organizations will grow in influence. The rest of us must pay attention to what they have to say as they are the ones who have experienced the disease and the harsh discrimination that often comes with it.

Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Saber Hossain Chowdhury

Member of Parliament (Bangladesh)

G. Venu Gopal

Chief Executive Officer, APAL (India)

Amar Bahadur Timalisina

Executive Director, IDEA Nepal

Kerstin Beise

Chair, YDTI (Indonesia)

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

INTERVIEW



Saber Hossain Chowdhury

Member of Parliament (MP), Bangladesh
 Honorary President, Inter-Parliamentary Union (IPU)
 Chairman, Parliamentary Standing Committee on Ministry of Environment,
 Forest and Climate Change, Bangladesh

<https://en.saberchowdhury.com>

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Laws should reflect the values of society

Saber Hossain Chowdhury is an incumbent Member of Parliament (MP) in Bangladesh. From 2014 to 2017, he was President of the Inter-Parliamentary Union (IPU), which aims to promote peace, democracy, and sustainable development around the world. In this role, he led the IPU's endorsement of the 2017 Global Appeal to End Stigma and Discrimination against Persons Affected

by Leprosy. Mr. Chowdhury is known for introducing and securing the passage of a bill that repealed the 1898 Lepers Act, a law from Bangladesh's colonial period that segregated leprosy patients from society and their families. The *Leprosy Bulletin* asked for his thoughts on how more people, and especially legislators, can be encouraged to take action against discriminatory laws in their countries.

LB (*Leprosy Bulletin*): Mr. Chowdhury, you introduced a Private Member's Bill in Bangladesh Parliament that was instrumental in securing the 2011 abolition of the discriminatory 1898 Lepers Act. How did you get involved in this issue and what was the driving force behind your efforts?

Mr. Chowdhury: Yes, I introduced the Bill and it became an Act of Parliament when it was enacted. As a public representative, I have always tried to champion issues relating to rights and ensure that the law applies equally to all without discrimination.



Mr. Saber Hossain Chowdhury in his role as Member of Parliament (MP) addressing the Jatiya Sangsad, the supreme legislative body of Bangladesh.

My involvement started when the Bangladesh office of Leprosy Mission International got in touch with me and requested my assistance in repealing the act. The Lepers Act was from Bangladesh's colonial era. It discriminated against

those with leprosy and stipulated segregation when it came to treatment. I took an immediate interest in the matter.

I interacted in person with those affected by the disease (including children) and listened to them as they talked about their needs. Repealing the act became a priority for me, and I am so happy this has been done.

LB: It has been over 10 years since the law was abolished. What effect do you think the abolition of the law has had? Have you noticed any changes in the lives of persons affected by leprosy in Bangladesh?

Mr. Chowdhury: From the point of view of their access to treatment, things are a little better, but in terms of their overall socio-economic condition, much work needs to be done. Mindsets and attitudes take time to change, and so we have to persevere.

LB: There are still over 100 laws around the world that discriminate on the basis of leprosy. People are making efforts to have these laws repealed. As someone who has succeeded in bringing about the abolition of one such law, could you offer some advice on how legislators can be persuaded to make changes?

Mr. Chowdhury: I am sure if you study the constitution of the countries where such discriminatory laws still exist, the principles of equality, equity and non-discrimination will feature clearly.

Further, laws should reflect the values of society and it is absolutely wrong and inequitable that we still continue to

carry burden of such discriminatory laws. This, coupled with the fact that advances in treatment protocols and medical science means that leprosy is a condition that can be safely treated in public hospitals, should persuade legislators in those countries to act and repeal such laws.

LB: WHO Goodwill Ambassador Yohei Sasakawa has led an annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy since 2006. You were involved in 2017 as the president of the Inter-Parliamentary Union when the IPU endorsed that year's appeal. What role do you think lawmakers can play in helping to resolve leprosy issues, and how can they be motivated to take up leprosy as an issue when it may not seem like a priority for them?

Mr. Chowdhury: As Goodwill Ambassador, Mr. Sasakawa has been a wonderful and outstanding champion and he has my deepest appreciation, regard, and respect for his untiring efforts to end the stigma and discrimination against persons affected by leprosy. It was an absolute honor and a singular privilege for me to lead the IPU when we endorsed that year's appeal.



Mr. Saber Hossain Chowdhury in his role as President of the Inter-Parliamentary Union (IPU) endorsing the 12th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy (New Delhi, India, 2017).

Lawmakers have a critical and pivotal role as they are mandated by the constitution to repeal, enact, or amend laws, as the case may be. This is their business, duty, and responsibility. Access to health for all is everyone's responsibility as is the requirement that all are treated equally and none are discriminated against.

So I sincerely hope and wish that lawmakers in relevant countries will make resolving leprosy-related issues their priority and act accordingly, even if no one in their own constituencies is affected by the disease. We are elected by our constituents, but our responsibility is to do what is good, right, and proper for the country in addition to working for those who elect us.

LB: The Goodwill Ambassador says that we need to build an inclusive society in which diversity is recognized and everyone — including persons affected by leprosy and persons with disabilities — can flourish. As someone who is active not

only in Bangladesh but internationally in cooperation with the United Nations, what do you think is required to build a society that leaves no one behind, as called for in the 2030 Sustainable Development Goals (SDGs)?

Mr. Chowdhury: A chain is as strong as the weakest link and hence if one amongst us fails, we all fail. We must embrace this spirit and make it clear to all that flourishing as a species is not possible when many are being left behind. It is an unfortunate fact that the world has become more unequal, and based on current trends and trajectory, achieving the SDGs will take us decades beyond 2030. The global pandemic has made the challenges even steeper.

We are in the midst of a climate and planetary emergency and we have to rethink and reimagine development, funding, governance, and how multilateralism can be revamped. It is a tall order but failure is not an option and hence we must rise to the challenge.

LB: Finally, do you have a message for readers of the *Leprosy Bulletin*?

Mr. Chowdhury: Our world desperately needs change. Rather than wait for others to bring this about, why not be the change you wish to see in the world? We can all make a difference.



Saber H Chowdhury | সাবের হোসেন চৌধুরী
@saberhc

At midpoint of ##SDGs, we are NOT on track to achieve any of them and in one instance (of #ClimateChange) there is actual regression. At current rate, we will achieve SDGs not in 2030, but 35 years later in 2065!! We must all roll up our sleeves and get to work. @IPUparliament

UNDRR Asia-Pacific @UNDRR_AsiaPac · Mar 10

Thank you @IPUparliament and @UNESCAP for organizing this important exchange with #parliamentarians on the need to accelerate action on #SDGs and #SendaiFramework.

Especially honoured to have @saberhc provide his insights on the critical roles of #MPs.

ipu.org/event/putting-...



Twitter post by Mr. Saber Hossain Chowdhury (@saberhc) about the need for Members of Parliament (MPs) to get involved in hastening progress toward the 2030 Sustainable Development Goals (SDGs) (posted March 11, 2022).

VIEWPOINT



G. Venu Gopal
CEO, Association of People Affected by Leprosy (APAL)

APAL is working for the socio-economic empowerment and welfare of persons affected by leprosy and their families who reside in leprosy colonies throughout India.

<http://www.apalindia.in>
 Twitter: @ApalIndia

Reflections on 16 years of APAL

Association of People Affected by Leprosy (APAL) is a national organization in India with a community-based network spread across 16 states and covering 800 colonies. APAL's plan and main aims are to make sure that persons affected by leprosy and their families become very strong economically and socially, are included in mainstream society, and live with dignity and awareness of their rights. Specific areas of work that we undertake, in cooperation with the government and other stakeholders, include community mobilization, awareness raising, empowerment, and advocacy.



"Interaction Meeting" of APAL representatives with state leaders of Uttar Pradesh (Nov. 22, 2021).

APAL's innovative approaches and mobilization skills have helped numerous dependent families and homeless persons affected by leprosy. Our efforts have resulted in a considerable change in the perceptions of the general community and health officials. Voices of the affected individuals are being heard, and stigma and discrimination focused on deformity is being replaced by a humanistic approach with professional and empathetic support. Effective coordination and sustained advocacy have helped APAL to achieve emancipation from stigmatized perceptions and develop a supportive fraternity with the government, non-governmental organizations, and changing communities.

Leprosy control and elimination in India still face many challenges. Although many of the theoretical and practical approaches of the past have been discarded, their careful

examination has provided insights for the future. Sustaining the gains made so far and further reducing the disease burden in India has led to an innovative and holistic approach that includes ongoing education, efforts to identify interventions to dispel stigma, promotion of children's education, empowerment of second-generation youth, and livelihood promotion for social inclusion and economic sustenance.

Over the past 16 years, APAL's efforts have included:

- Baseline survey of leprosy colonies
- Grassroot-level programs for colony leaders and persons affected by leprosy
- Networking among colonies
- Strengthening of state leaders and a team of colony members for effective working in the states
- Women and youth empowerment workshops
- Capacity-building training programs for state leaders, colony members, and youth
- Raising awareness of human rights issues of persons affected by leprosy
- Working with the government, WHO, NGOs, national and international agencies for mainstreaming of people
- Working in collaboration with Sasakawa-India Leprosy Foundation (S-ILF) for the vocational pieces of training, higher education, and coaching for school-age children of persons affected by leprosy
- Promoting awareness of leprosy, the Rights of Persons with Disabilities (RPWD) Act, COVID-19 precautions, and prevention of disabilities
- Advocating for Unique Disability identification (UDID) cards, social entitlements, aids and appliances, and livelihood and land issues of persons affected by leprosy

Going forward, our main aim will continue to be to provide opportunities to persons affected by leprosy and their families to live with dignity in mainstream society.

LETTER



Amar Bahadur Timalisina
Executive Director, IDEA Nepal

Founded in 1998, IDEA Nepal is a national level organization run by persons affected by leprosy that is dedicated to the principle that individuals whose lives have been challenged by the disease have the right to full and equal participation in society.

<https://idealeprosy.org.np>

<https://www.facebook.com/ideanepal1998>

Current status of persons affected by leprosy in Nepal

I am attempting to use words to give you a picture of the conditions of persons affected by leprosy in Nepal. Not surprisingly, I wish to show both the achievements of the last 10 years and newly emerging challenges.

Nepal is a federal democratic republic that is known for natural beauty and cultural diversity. Our landlocked country has also been called “underdeveloped,” and illiteracy and discrimination against persons affected by leprosy are ongoing issues. Data shows that literacy rates for various population groups have been increasing. Discrimination against persons affected by leprosy, however, is taking new forms rather than diminishing.



Playing traditional music associated with weddings and other happy events to defy discrimination and celebrate IDEA's 20th annual International Respect & Dignity Day (Mar. 11, 2018).

In the past, discrimination was overt. Persons affected by leprosy would be isolated to an area far from the community. These days, discrimination is more subtle, but it is just as potent as before. Since the government of Nepal declared the elimination of leprosy, data seems to show a decrease in the number of diagnosed cases. Most of Nepal's laws give the impression that discrimination has ended as well, but communities continue discriminatory practices regardless of what the laws say.

COVID-19 made everyone think of survival before everything else. For social distancing, education moved to digital

platforms. The move to digital solved some problems while creating or worsening others. Despite promises of inclusion, students affected by leprosy, and especially those with leprosy-related disability, generally did not experience an improvement in their situation.



“Inception Workshop on Non Formal Education to the Affected Community in Nepal” organized by IDEA Nepal with the support of the Sasakawa Health Foundation (Lalgadh Leprosy Hospital, Aug. 19, 2021).

IDEA Nepal advocates for the dignity of persons with lived experience of leprosy. In recent years, the organization has been emphasizing restoration of dignity through economic

rehabilitation. As a representative of IDEA Nepal, I believe that economic rehabilitation is the approach that has the most potential to improve the situations of persons affected by leprosy in our country.



Distribution of livelihood restoration support for 40 persons affected by leprosy who lost their livelihoods as a result of COVID-19 (Morang District, Nepal, Aug. 20, 2021).

“Don't forget leprosy” campaign boosts message

Diversion of resources, movement restrictions, and other measures implemented during the COVID-19 pandemic have disrupted leprosy services and increased burdens on already vulnerable persons affected by leprosy. In this context, the Sasakawa Leprosy (Hansen's Disease) Initiative implemented a 10-month campaign with the message “Don't forget leprosy.” The campaign schedule gave special consideration to World Leprosy Day, which has been observed every year on the last Sunday of January since 1954. In 2022, the last Sunday fell on Jan. 30. The Initiative supported 32 organizations — NGOs, organizations of persons affected by leprosy, universities, medical associations, and other institutions — in 13 countries to boost messaging in the weeks around this date.

Jan. 10-20

Centro de Medicina de Reabilitação da Região Centro – Rovisco Pais, Portugal



Video contest organized based on the “Don't forget leprosy” theme and winning video shared through social media on World Leprosy Day. Facebook post of the winning video: <https://fb.watch/bXWA5TSGMg/>.

Jan. 25

Association Sénégalaise de Lutte Contre la Lepre et les Maladies Tropicales Négligées (ASCL/MTN), supported by German Leprosy and Tuberculosis Relief Association (GLRA/DAH), Senegal



Event held to launch the “Don't forget leprosy” campaign in Senegal.

Jan. 27

Movimento de Reintegração das Pessoas Atingidas Pela Hanseníase (Morhan), Brazil



Health education and active search for new leprosy cases carried out at the Lessa de Andrade Polyclinic, located in the Madalena neighborhood of Recife, a large urban area in northeastern Brazil.

Jan. 27

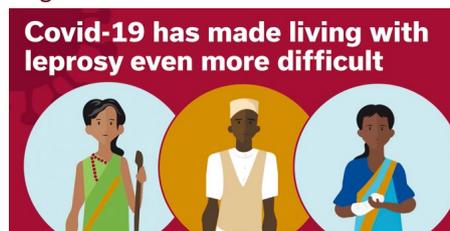
St Joseph's Leprosy Hospital, Father Muller Charitable Institutions, India



Guest lecture organized at Father Muller Medical College Hospital's Decennial Memorial Hall in Mangalore, Karnataka, India, to commemorate World Leprosy Day.

Jan. 28

The Leprosy Mission International (TLMI), United Kingdom



Video created and spread widely through social media to raise awareness of the difficulties that persons affected by leprosy are facing amid the coronavirus pandemic to make sure no one is left behind. Watch video at <https://fb.watch/c2Kf2x203/>.

Jan. 29-31

Eijkman Oxford Clinical Research Unit / University of Oxford, supported by Papua Health Research and Development Center, Ministry of Health, Indonesia



Photo exhibition “Stories from the Island” at the Balitbangkes Papua office, Jalan Ahmad Yani Jayapura, Indonesia.

Jan. 30

Advancing Leprosy and disadvantaged peoples Opportunities society (ALO), supported by The Leprosy Mission (TLM)-Bangladesh



Rally, discussion session, and distribution of blankets held at the Matiranga Upazila Health Complex in Bangladesh. Government officials participated in the events.

ing in the weeks around World Leprosy Day

Feb. 3 The Leprosy Mission (TLM)-Nigeria



Road walk held to commemorate World Leprosy Day 2022. Flyers were distributed to raise awareness of the signs and symptoms of leprosy.

Feb. 6 Acworth Leprosy Hospital Society for Research, Rehabilitation & Education in Leprosy, India



Leprosy awareness program organized in Panvel, Maharashtra, India, to share information about leprosy with civil society.

Feb. 7 Association of People Affected by Leprosy (APAL), India



Awareness-raising activity conducted in collaboration with Priyanshi Educational, Cultural & Social Society (PECSS) at Government Post Graduate (PG) Girls College of Bheelpura Panchayat in Hoshangabad, Madhya Pradesh. A quiz on leprosy was given and the winner was awarded a prize.

Feb. 9 PerMaTa South Sulawesi, supported by Yayasan Dedikasi Tjipta Indonesia (YDTI)



Appearance on Indonesian television by WHO Goodwill Ambassador Yohei Sasakawa along with three other spokespeople to appeal for wider understanding of leprosy and related issues. Recording available at <https://www.youtube.com/watch?v=Ez4A-GyHCHs>.

Feb. 14 Sasakawa-India Leprosy Foundation (S-ILF), India



Street play organized in Belanki village, Sangli, to bring awareness towards persons affected by leprosy in India.

Feb. 15 Atma Swabhimana, India



Outreach to students and administrators at three government high schools in the city of Dhanbad, India. Information on leprosy disseminated for wider awareness, acceptance, and public support for persons affected by leprosy.

Feb. 16-17 Uganda National Alliance against Leprosy (UNALEP), supported by German Leprosy and Tuberculosis Relief Association (GLRA/DAH), Uganda



Sensitization meetings held in Karambi and Maliba Sub-Counties in Uganda.

Feb. 20 Purple Hope Initiative Nigeria (pHIN), supported by German Leprosy and Tuberculosis Relief Association (GLRA), Nigeria



Radio broadcast from RADIO ONE 103.5 FM LAGOS in Nigeria to talk about leprosy and the "Don't forget leprosy" campaign.

Feb. 25 Greater Tenali Leprosy Treatment and Education Scheme Society (GRETNALTES), India



Leprosy awareness rally conducted with the National Cadet Corps (NCC) students at Tenali in Andhra Pradesh, India.



WISH LIST



Kerstin Beise
Chair, Yayasan Dedikasi Tjipta Indonesia (YDTI)

Originally from Germany, Kerstin Beise has been living in Indonesia since 1998, when she received a scholarship to study at Makassar University in South Sulawesi. She has years of experience in comprehensive rehabilitation, community inclusive development, and stigma reduction.

For each issue, the *Leprosy Bulletin* asks a person affected by leprosy or an individual involved in leprosy-related work for two to three things that they wish could happen. We ask contributors to be bold in order to stimulate thinking and inspire new approaches.

- 1 I wish that government and support organizations would recognize that there are still many people in Indonesia who need medical and rehabilitation services after treatment for leprosy and cannot receive them due to reduced attention.
- 2 I wish that more leprosy control programs in Indonesia would actively involve people affected by leprosy in their work, such as dissemination of information and peer-to-peer support, which has proven to be very effective.
- 3 I wish that governments would focus more on zero disabilities and zero discrimination as a way to achieve elimination.

SPOTLIGHT

Yayasan Dedikasi Tjipta Indonesia (YDTI)

YDTI is a non-governmental organization founded by Kerstin Beise that started out in 2016 as a representative office of a Netherlands-based consultancy cooperative called Dare This. In 2020, Kerstin and her local partners established an independent Indonesia-based entity under the name Yayasan Dedikasi Tjipta Indonesia (Dare This Indonesia Foundation).

Trained as a physiotherapist, Kerstin worked for the non-governmental organization NLR for 14 years before starting YDTI. During her time at NLR, she collaborated on many projects and activities with the people's organization PerMaTa, and especially with PerMaTa South Sulawesi. As she was starting her own organization, she spoke with PerMaTa South Sulawesi leaders about how they could work together. In Kerstin's words, "There was a strong desire and commitment from both sides to strengthen the work of DPOs [disabled people's organizations] on leprosy in Sulawesi, especially as attention to the needs of people affected by leprosy has decreased in recent years and the leprosy control program and international support organizations increasingly focused on other important measures such as chemoprophylaxis. We saw that we could complement each other



Founder of YDTI, Kerstin Beise, meeting an old companion in the fight against stigmatization and discrimination on World Leprosy Day in Bone, South Sulawesi (January 2022).

very well: with Pak Ai Kadri and Yuli [of PerMaTa] we have persons affected by leprosy as actors who have many years of experience in peer support and advocacy, while YDTI brings in capacity in the areas of proposal writing and project management."

SASAKAWA
LEPROSY
 HANSEN'S DISEASE
INITIATIVE

WHO Goodwill Ambassador's Leprosy Bulletin No.108

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