3rd Global Forum of People´s Organizations on leprosy/Hansen´s disease

Letter with recommendations to stakeholders

Bali, July, 2025

We, the organizations of persons affected by persons affected by leprosy/Hansen´s disease gathered together in Bali on the 4th, 5th and 6th of July, at the 3rd Global Forum of People´s Organizations on Hansen´s disease facilitated by Sasakawa Leprosy (Hansen´s disease) Initiative.

Before coming to Bali, we undertook needs assessments to bring the voices from the grassroots to the forum. At the forum, we engaged in discussions based on our needs assessments and, under a spirit of dialogue and cooperation, exchanged views on common problems and solutions to those.

We recognized that, while medical treatment exists, many people still struggle to have access to consistent medicines, rehabilitation and psychosocial support — especially in rural or remote areas. People continue to face severe stigma and discrimination — not only from society, but sometimes even from within their own families or communities. This leads to isolation, loss of livelihoods, children being denied education, and many losing hope of living a life with dignity and enjoying opportunities on an equal basis with others.

Our collective responsibility is to identify what must be changed — in our organizations, in the practices of stakeholders and policy-makers and in the systems that still fail to uphold the rights and dignity of those with lived experience of leprosy/Hansen´s disease.

Building on the recommendations from the previous Global Forums, and based on the needs and problems we have identified, as well as the solutions to those, we call upon:

a) All stakeholders to actively support the commitments, recommendations and action plans issued by us at the Global Forum.

b) National and local government to allocate funds and human resources, as well as develop clear strategies in consultation with the representative organizations of persons affected by leprosy/Hansen´s disease to: recognize leprosy care as a human right and guarantee early diagnosis and timely treatment; make every effort in abolishing or amending discriminatory legal frameworks, enact anti-discrimination laws and enforce legal protection and remedies for human rights violations, including violations to the right to health; recognize persons affected by leprosy/Hansen´s disease as being entitled to the rights provided by national disability laws; include our voices in policy-making, service design and delivery, and monitoring and evaluation; re-examine and re-define the elimination goal in order to reflect realities on the ground; allocate dedicated budget lines for providing free or affordable medicines for treatment of reactions and other conditions including wound care, rehabilitation, and mental health care for persons affected by leprosy/Hansen´s disease; provide medicines and care consistently in all areas, especially rural and remote ones, involving our leaders in budget planning and national, sub-national and local health committees, and adding leprosy to health insurance and social protection schemes. The next annual national planning should include anti-discrimination measures and the standard of care of persons affected by leprosy/Hansen´s disease. For accountability purposes, we urge national governments to engage in an open dialogue with organizations of persons affected by leprosy/Hansen´s disease and the Global Forum´s Oversight Committee; and to report on progress and discuss pragmatic manners of implementing the recommendations of the Global Forum.

c) The World Health Organization, the United Nations monitoring mechanisms, pharmaceutical companies and national Leprosy Programmes to: be accountable with open and accessible communication channels and regular reporting, ensure uninterrupted leprosy/Hansen´s disease medicine, as well as to improve supply chain management; they should also undertake every effort to produce new medical technologies and drugs for improving prevention and care of leprosy/Hansen´s disease.

d) Public and private development initiatives to produce specific programs for: including persons affected by leprosy/Hansen´s disease in the search for solutions that are equitable, inclusive and sustainable and removing any obstacles faced by individuals affected by leprosy/Hansen´s disease, including those living in colonies to the right to development, which includes access to a minimum standard living of living. Programs should include responses to new threats, such as conflicts and climate change, that severely impact the livelihoods and human security of persons affected by leprosy/Hansen´s disease.

e) All leprosy stakeholders, including the organizations of persons affected by leprosy/Hansen´s disease to: report every case of discrimination and human rights violations on the grounds of leprosy/Hansen´s disease to the correspondent authorities and monitor action taken.

f) Healthcare workers to: adequately treat leprosy reactions and complications including wound care, treat persons affected by leprosy/Hansen´s disease with respect and without discrimination in all healthcare settings, which should be available and accessible. For such an ending, national governments, international and national non-governmental organizations and intergovernmental organizations should take tangible actions to train medical officers and frontline healthcare workers on leprosy/Hansen´s disease medical and rights-based care delivery without delay.

g) Healthcare systems to: put in place grievance redressal mechanism exclusively for leprosy and ensure accountability for service failures; undertake audit in line with other programs, also with the adequate provision of remedies and reparation in case of poor health outcomes and disability due to service failures and/or negligence.

h) Public and private schools to: accept and support children affected by leprosy/Hansen´s disease and their families; and to include anti-discrimination education for students, teachers, and parents in their respective curricula and involve persons affected by leprosy/Hansen´s disease in awareness activities within schools.

i) Traditional, religious and community leaders to: speak publicly to challenge stigmatization and harmful beliefs and practices and to welcome persons affected by leprosy/Hansen´s disease in community and faith gatherings. They should commit to hosting community dialogues as part of their regular activities that explain that leprosy/Hansen´s disease is not a curse or the result of any wrongful behaviour and by enabling and endorsing people re-joining community and collective activities.

j) The private sector and businesses to adapt internal policies and regulations to: hire persons affected by leprosy/Hansen´s disease and treat them equally in the workplace. Businesses should create non-discriminatory hiring policies, provide fair job training and pay persons affected by leprosy/Hansen´s disease on equal terms with others; and support income-generation activities led by persons affected by leprosy/Hansen´s disease, especially women.

k) International and national non-governmental organizations to: be truly inclusive by ensuring the participation of persons affected by leprosy/Hansen´s disease in decision-making and by providing job opportunities. Furthermore, they should promote short-medium- and long-term solutions to poverty.

l) National human rights institutions and legal aid services to: empower the members of our organizations to know their rights and how to claim them. We want their support in reporting and resolving discrimination cases, removing outdated discriminatory laws, running legal literacy training in local languages, setting up easy to use and safe complaint systems and offering free legal aid when needed.

m) Given that leprosy/Hansen´s disease is one of the oldest diseases, associated with stigmatization in different cultural backdrops and throughout the history of humanity, media and journalists should be aware of their role in removing harmful stereotypes and for that ending they should: share true stories about leprosy/Hansen´s disease and persons affected by it to change public attitudes and stop spreading myths. Narratives should be dignifying and never resource to derogatory language or other negative references or images.

n) Other community-based and disability organizations to: partner with us on joint awareness campaigns, funding bids and training. We want to share meeting spaces, resources and ideas. They can stand with us in advocating for our rights, work together on anti-stigma days and support each other in community mobilization and government advocacy.

We urge all governments and stakeholders to move as quickly as possible towards the realization of our recommendations. We also demand from them proper budget allocation to meet the targets herewith expressed and to adopt inclusive approaches and open dialogue, ensuring the right to participation and promoting transparent sharing of information and accountability. We count on the Global Forum´s Oversight Committee to monitor progress and we expect real progress to be made before the next International Leprosy Congress.