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.

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.

Building on the recommendations from the previous Global Forums, and based on the needs, problems and solutions we have identified at the grassroot level, as well as during our discussions at the forum, 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; abolish or amend discriminatory legal frameworks, enact anti-discrimination laws and enforce legal protection and remedies for human rights violations; 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 the continuum of care in all areas, especially rural and remote ones; involving our leaders in budget planning and national, sub-national and local health committees; adding leprosy to health insurance and social protection schemes.
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; improve supply chain management; undertake every effort to produce new medical technologies and drugs for improving prevention and care.
d) Public and private development initiatives to produce specific programs for: promoting the right to development for persons affected by leprosy, including those living in colonies; and address new threats, such as conflicts and climate change.
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.
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 include anti-discrimination education for 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.
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.; and support income-generation activities led by persons affected by leprosy/Hansen´s disease, especially women.
k) International and national non-governmental organizations to: ensure the participation of persons affected by leprosy/Hansen´s disease in decision-making and provide 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) We also urge the media to cooperate with us in joint awareness campaigns and community organizations and disability groups to partner with us in joint actions against stigma, as well as in sharing meeting spaces, funding proposals and trainings.

We call upon all governments and stakeholders to act urgently to implement our recommendations. We also call for adequate budget allocations to achieve the objectives outlined here, and for the adoption of inclusive approaches and open dialogue, ensuring the right to participation, transparent information-sharing, and accountability. We rely on the Global Forum Monitoring Committee to track progress, and we expect tangible improvements before the next International Leprosy Congress.