

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

Letter of Commitment

Bali, July, 2025

We, the organizations of 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, reaffirm our unwavering commitment to promoting the rights, dignity, inclusion, and well-being of persons affected by leprosy/Hansen's disease and their families.

Before coming to Bali, we undertook needs assessments to bring the voices from the grassroots to the forum. At the forum, we listened deeply to each other's stories, shared our struggles and successes and spoke honestly about the barriers we still face — from stigmatization, discrimination and poor access to healthcare, to lack of livelihoods, legal protection and participation in decision-making.

We recognize that true change must start with us — and that our strength lies in working together, raising our voices and standing in solidarity. This letter of commitment reflects our shared vision: that all persons affected by leprosy/Hansen's disease, in every country and every territory, will live with dignity, equal rights and full participation in society.

Our organizations pledge to work together and collaboratively with stakeholders at all levels to ensure that the needs and rightful demands of the people are holistically and fully addressed.

We know this will not happen overnight. But through the actions herewith, we commit to taking practical steps, holding each other accountable and building strong organizations that will continue this work for years to come.

We are committed to address the issues and gaps identified by our needs assessments and discussions at the forum. And to do that, we uphold our firm determination to take direct action as given below:

- a) In our organizations, we will ensure that decisions are autonomously and independently made by persons affected by leprosy/Hansen's disease, who must be the owners of their organizations; we will also pursue leadership development with emphasis on the grassroots, effective and efficient management, transparency and accountability, needs-based programs and inclusive participation in decision-making; we will ensure internal democratic procedures and equal access to opportunities among us.
- b) In our territories of action, we will work towards restoring health, dignity and autonomy of persons affected by leprosy/Hansen's disease, by directing our efforts to free our territories from the disease, its consequences, discrimination and poverty. After diagnosis, during and after treatment, we will accompany, support and counsel the people and their families. Our work will always ensure that persons affected by leprosy/Hansen's disease develop confidence and resilience in order to create a ripple effect.

- c) At the national level, we will advocate for leprosy/Hansen's disease care to be framed as a human right; for national leprosy/Hansen's disease programs to implement it effectively; for governments to accurately report on the number of new cases in country; towards the abolishment or amendment of any discriminatory legal frameworks, as well as the enactment of anti-discrimination legal frameworks; and for the implementation of oversight and complaint accessible and easy to use mechanisms. We will also mainstream legal literacy into all our activities, so that persons affected by leprosy/Hansen's disease know their rights and how to claim them. We will report every case of human rights violation to the relevant authorities and monitor the actions taken.
- d) At the global level, we will organize ourselves in an oversight committee composed by persons affected by leprosy/Hansen's disease who represent organizations of persons affected by leprosy/Hansen's disease from all regions and whose mandate will be of monitoring both national and international policies and implementation, and making governments, donors, pharmaceutical companies and intergovernmental agencies accountable. For the implementation of the oversight committee's mandate, its members should develop a Terms of Reference, with clear attribution of mission, roles and responsibilities. By the same token, a clear and pragmatic plan of the activities to be implemented to realize the mission of the oversight committee should be developed. The oversight committee should be elected democratically by the organizations of persons affected by leprosy/Hansen's disease, should not go beyond two representatives per region and be renewed periodically. The oversight committee will respond to the calls of national and local organizations in situations where the latter cannot raise their voices in a safe manner or when they are not properly heard. The members of the oversight committee will be responsible to systematically collect information about the progress of the implementation of the commitments and recommendations of the Global Forum, including proactively calling relevant stakeholders to share their activities on a regular basis. The organizations of persons affected by leprosy/Hansen's disease will be responsible for sharing relevant information with the oversight committee. Without depending on the availability of funds, the oversight committee will meet virtually every three months to share the information and assess progress, bottlenecks and respond to emergency situations. The oversight committee will seek funds to meet in person once a year. The oversight committee will issue reports twice a year. The oversight committee will report to the Global Forum. More specifically, the oversight committee will report and be accountable to the organizations of persons affected by leprosy/Hansen's disease, especially those who participated at the 3rd Global Forum and who elected the members of same committee.

Through these actions, we commit to building strong, inclusive, and sustainable organizations that protect rights, reduce stigma and discrimination, and create opportunities for persons affected by leprosy/Hansen's disease to thrive with dignity.