

Statement by International Federation of Anti-Leprosy Associations (ILEP) to NTD STAG September 2022

ILEP is a consortium of 14 international NGOs, working in 63 countries, that share a commitment to zero leprosy. By zero leprosy, I mean four interconnecting zeroes: zero transmission of leprosy, zero patients without treatment, zero leprosy-related disability, and zero social exclusion or leprosy-related stigma.

ILEP has embraced the WHO NTD Road map, the WHO global leprosy strategy which aligns with it, and the recently launched WHO Skin NTDs strategic framework. These have had significant implications for the leprosy world and for ILEP's role within it.

Under the heading of accelerated program action, ILEP members continue to support countries to take postexposure prophylaxis to scale, while researching new preventive approaches. We support the work being done by the Global Partnership for Zero Leprosy, with WHO, in developing target product profiles for diagnostic tests for leprosy infection and leprosy disease. And we continue to focus on problems in the supply of leprosy medications. And we're participating in a WHO workshop in November around the challenges of anti-microbial resistance in leprosy.

Under the heading of country ownership there is ongoing dialogue in ILEP on the theme of sustainability. Earlier this year, for example, we had 300 practitioners discussing how to bring about sustainable involvement by ILEP members in active case detection, and ILEP's role in supporting health system strengthening.

Under the heading of integration, there is ongoing dialogue – sometimes debate – on how best to integrate leprosy services, usually with other Skin NTDs. The debate is because we recognise huge advantages for all NTDs from **joint programs on, for example, active case detection, contact tracing, mapping, management of disease complications, disability prevention, and training. But at the same time we** recognise that integration carries with it some risks for leprosy:

- **The risk of erosion of the leprosy expertise that has been built up over the years, which is important because leprosy can be a difficult disease to diagnose and manage**
- **The risk of overloading health workers, so that leprosy, which they may not see very often, gets forgotten again**
- **The risk that leprosy is regarded *only* as a skin disease, so that the importance of nerve function assessment for accurate diagnosis and treatment is completely forgotten, and the need for instruction in disability prevention is neglected or overlooked**
- **The risk of loss of focus for donors and partners committed to leprosy**

Under the heading of mainstreaming, there has already been a steady progression from ILEP members seeing themselves as implementers, to ILEP members seeing their role as primarily around technical support. In this regard, our current strategy has key goals in five thematic areas:

- First, formation of a global framework and strategy to build and sustain leprosy capacity
- Second, work with WHO on globally consistent leprosy data standards and methodologies, which we hope will lead to more accurate reporting
- Third, ensuring readily available services related to mental wellbeing in leprosy
- Fourth, fostering active engagement by persons affected by leprosy

- And fifth, innovation through research, proof of concept, and application of game-changing technologies and processes

ILEP shares WHO's concern about the decline in leprosy new case detection during the first year of the Covid pandemic, and the only slight recovery in 2021. Reported new case numbers remained 30% below the previous trendline. We urge the STAG to recommend that leprosy be included among the group of NTDs that are the subject of detailed study on the impacts of the pandemic.

Thank you for your attention

A handwritten signature in blue ink, consisting of a large, stylized 'G' followed by a horizontal line and a checkmark-like flourish.

Geoff Warne
CEO, ILEP