

## **Speech by ILEP CEO to 2<sup>nd</sup> International Symposium at the Vatican on Hansen's Disease January 2023**

Good afternoon, everyone. I'm CEO of the International Federation of Anti-Leprosy Associations, or ILEP. We are a consortium of 14 international NGOs that share a commitment to achieving a world free from Hansen's disease or leprosy. I'm happy that three of our member associations are co-sponsors of this conference: that's Sasakawa Health Foundation, Fondation Raoul Follereau and AIFO Italy. Along with our colleagues at Novartis, we're also one of the founding partners of the Global Partnership for Zero Leprosy. In ILEP's terms, zero leprosy means a world in which there's zero transmission of leprosy, zero new disability caused by leprosy, and zero leprosy-related stigma and discrimination. Triple zero.

The question before us is how we work towards zero leprosy, specifically referring to the conclusions and recommendations from the first Vatican symposium in 2016. From the perspective of ILEP, I make four remarks about that.

First, it was stated in 2016 and you've heard it several times yesterday and today: every new case of Hansen's disease or leprosy is one case too many. Some of the key targets in the WHO Global Leprosy Strategy 2021-2030 are a 70% reduction in new cases, a 90% reduction in new child cases, and a 90% reduction in new cases with visible impairments. These are challenging targets, but we think they may be achievable with a rapid and widespread scale-up of existing tools, and the development of new tools to combat transmission of the disease. ILEP members continue to work with governments on the scaling up of current best practices, and on supporting training and building of capacity in the health services, and we are also involved in supporting research and the piloting of new tools.

Second point. As I've said, the big reduction in new case numbers that's targeted in the WHO strategy is challenging, but eliminating leprosy-related stigma and social exclusion is a far tougher challenge. ILEP members continue to urge governments and community leaders to combat discrimination wherever it comes to our attention, and to ensure that human rights are respected. And as you've heard at some of the presentations yesterday, ILEP members are working to enable education and livelihoods and through the formation and support of self-help groups and people's organisations, which are some of the ways of combatting the negative effects of social exclusion. But that's nowhere near enough. More widespread activism is needed. It seems to me that religious leaders have a vital role here and need to redouble their efforts to change hearts and minds in their congregations and their communities. We would love to see, and to contribute to, interfaith dialogue on practical strategies to accomplish this.

Third point. You heard yesterday from Brent Morgan, that ILEP maintains a database of all known discriminatory laws and regulations. These still exist in far too many countries. They are designed to prevent people affected by Hansen's disease or leprosy from participating in many of the ordinary activities of life: getting a job, using public transport, being a candidate for public office, being married, entering a country, casting a vote. These laws, even when they are not actively being enforced, are deeply offensive and in some cases downright threatening to persons affected by leprosy. ILEP and our Member agencies will continue, alongside people's organisations and other NGOs, to call for repeal or amendment of these laws. But this is a long road, and calls for change often fall on deaf ears. We invite all stakeholders in this symposium to talk to us about discriminatory laws that may be in force in their countries and, collaboratively with persons affected by leprosy and organisations that work with them, to use their influence to get these laws repealed.

Final point. Let me quote from one of the recommendations from the 2016 symposium: 'Persons affected by leprosy or Hansen's disease must be seen as the main actors in the fight against discrimination and the denial of rights that they experience.' ILEP has been impressed and encouraged to see, since 2016, the increasing self-organisation and empowerment of organisations of persons affected by Hansen's disease or leprosy. We've been hearing at this symposium about how people's organisations are effectively and powerfully advocating for themselves, at local and national level. I recognise the achievement of the organisations represented here, and others like them, and the support and encouragement of IDEA International, Special Rapporteur Alice Cruz, some ILEP members, and also the mutual support that people's organisations offer to one another. But in some countries, such organisations either don't exist or they are fragile. ILEP wants to work productively and respectfully, in dialogue with persons affected by leprosy, to understand how best we should support the birth of such organisations and a path towards their greater autonomy, empowerment and capacity.

Thank you.