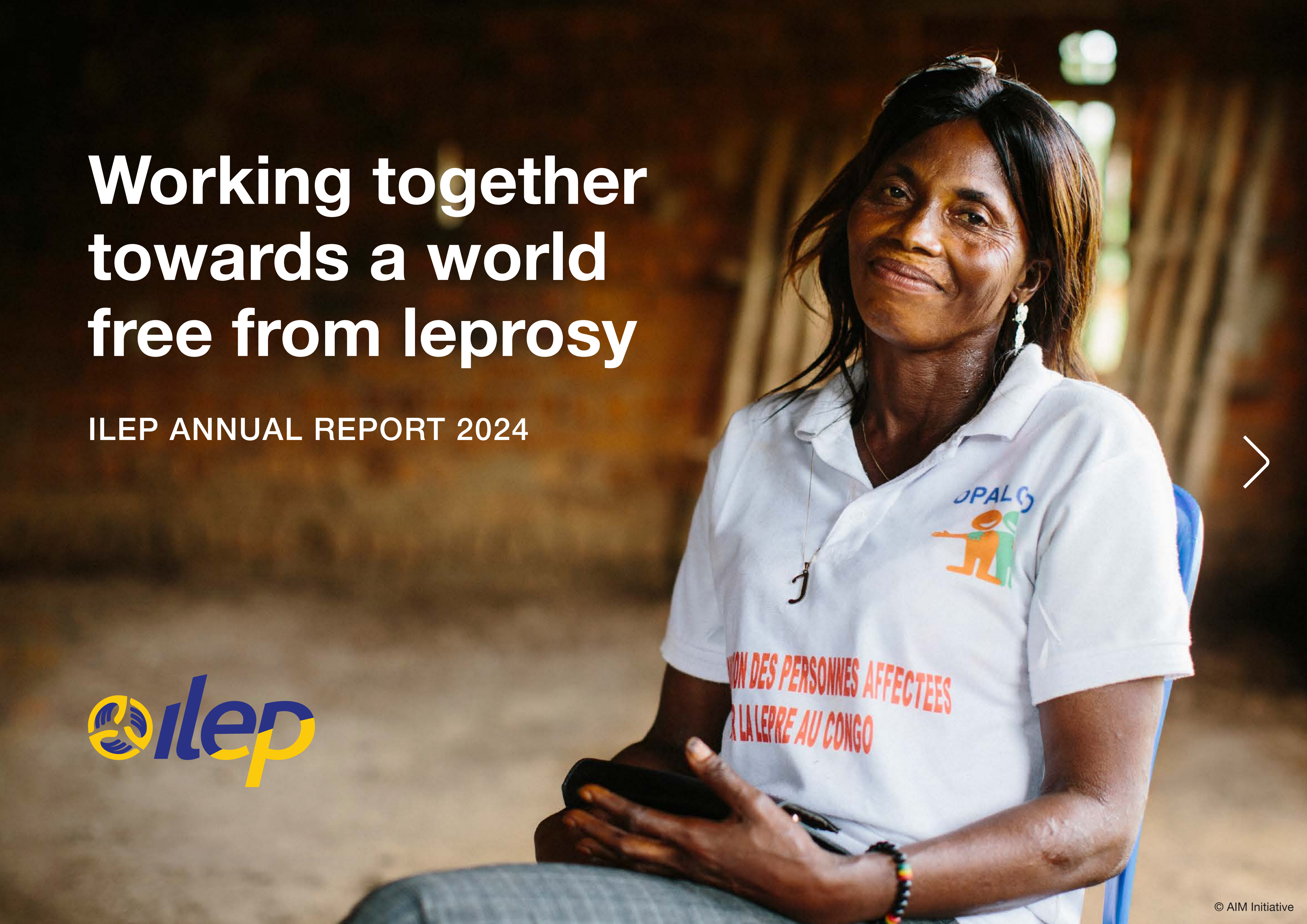

Working together towards a world free from leprosy

ILEP ANNUAL REPORT 2024

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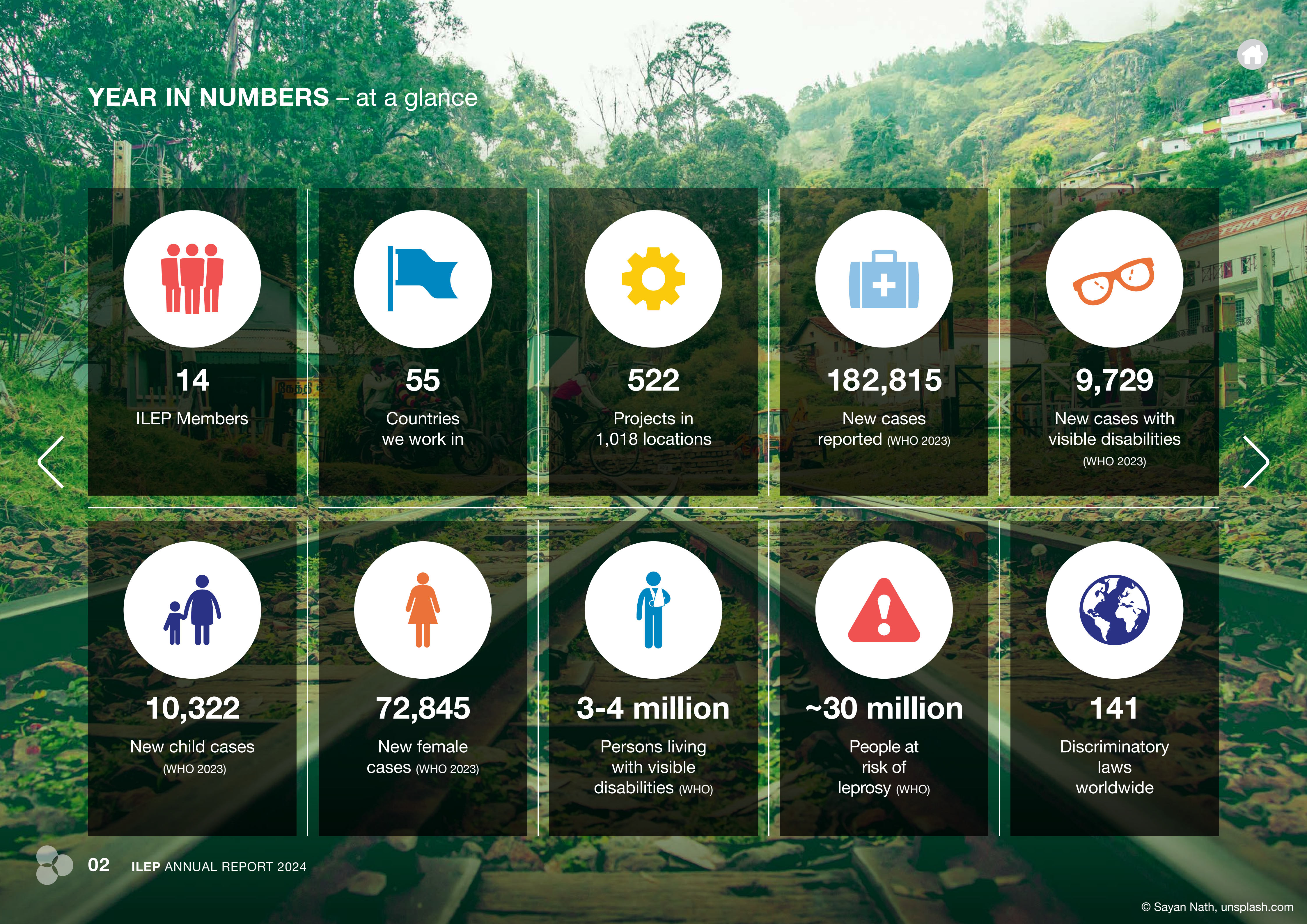

YEAR IN NUMBERS – at a glance

14
ILEP Members

55
Countries we work in

522
Projects in 1,018 locations

182,815
New cases reported (WHO 2023)

9,729
New cases with visible disabilities (WHO 2023)

10,322
New child cases (WHO 2023)

72,845
New female cases (WHO 2023)

3-4 million
Persons living with visible disabilities (WHO)

~30 million
People at risk of leprosy (WHO)

141
Discriminatory laws worldwide

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Working together to stop leprosy, prevent disability and break the stigma resulting from leprosy.

CONTENTS

PRESIDENT'S REPORT

Brent Morgan, ILEP President

Broadening the mandate

> **"We embraced the vision of leveraging our expertise and infrastructure to benefit other skin NTDs."**

The ILEP member CEOs set aside a day each year as an in-person 'CEO Summit' to look in detail at an issue or challenge affecting all ILEP members. In November 2024, the CEO Summit focused on the question of whether ILEP should broaden its mandate beyond leprosy to incorporate other neglected tropical diseases (NTDs) that affect the skin. Several ILEP members are already doing so. The question in front of us was whether this should be our policy as a consortium.

As always, this resulted in a robust yet cordial discussion among peers who already collaborate actively in many activities towards our global goal. Some members already incorporate certain other severely stigmatizing NTDs – Buruli ulcer, lymphatic filariasis, yaws – in their programs: they see these diseases as being very similar to leprosy as regards the ongoing impact on persons affected by them. Other members have large-scale TB control programs, or a primary emphasis on rehabilitation or on general healthcare in poor communities: their attention is on the effective integration of leprosy within these programs.

Others have made deliberate decisions to focus on leprosy, considering that there are still 200,000 new cases each year with only a very slow downward trend.

The provisional conclusion was that leprosy should continue to be ILEP's core mission, and the mandate should not be extended by adding any specific set of skin NTDs. However, we recognised that other skin NTDs could benefit greatly from ILEP's depth of expertise, its many years of experience, and the impressive infrastructure available for leprosy. We embraced the vision of strategically leveraging our expertise and infrastructure to benefit other skin NTDs. During 2025 we will continue to explore how best to do this, while building closer relationships with other organizations working in skin NTDs, in preparation for a new ILEP strategy from 2026.

MESSAGE FROM THE CEO

Geoff Warne

Boosting participation

> **“People affected by leprosy have the right to participate in relevant ways in the decisions that affect them.”**

The principles of dignity and inclusion mean that people have the right to participate in relevant ways in the decisions which organisations make that affect them. ILEP’s Statement on Participation (shown on page 17 of this report) aims to ensure that persons affected by leprosy have the space and the support for meaningful participation in our decision-making processes.

The question, inevitably, is how we can make such a statement real. One way we do this is through ILEP’s Advisory Panel, which was reappointed in 2024 and consists of seven persons from seven different countries. Through linkages with people’s organizations in their own countries and beyond, the Panel can bring to ILEP the views and perspectives of persons affected by leprosy in an increasing number of countries.

Another way is through nurturing the start-up and growth of organisations of persons affected by leprosy. These organisations have the potential to make a major contribution to challenging stigmatising attitudes, defending people’s rights, and ensuring a voice in policy and other decisions at different levels of government.

This year, ILEP members joined representatives of people’s organisations in a global webinar to discuss how ILEP members can best support these organizations to flourish in every endemic country, without resulting in dependency. The proceedings were reported in *Leprosy Review.*

A third approach is through the Neglected Tropical Disease (NTD) Inclusion Score Card, a tool developed by ILEP that enables organizations to self-assess where they stand in terms of the participation by persons affected by leprosy and other NTDs in their programmes and decisions. ILEP continues to promote the use of this tool not only among its own members but also among the wider group of NGOs involved in NTDs.

Our hope is that through these mechanisms and others, we will a steady increase in confident, effective participation by persons affected by leprosy – with positive impacts for all of us.

ILEP 2021-2025 Strategy at a Glance

Towards a world free from leprosy

The International Federation of Anti-Leprosy Associations (ILEP) is a consortium of autonomous, international NGOs working for a world free from leprosy: **zero transmission of leprosy, zero patients without treatment, zero leprosy-related disability and zero exclusion.** This strategy articulates five significant global ‘game-changers’ that ILEP aims to tackle and resolve through active collaboration.

This is a short ‘strategy at a glance’: the full strategy can be viewed on the ILEP website.

KEY STRATEGIC GOALS

Game-changing goals towards which ILEP aims to make significant progress during 2021-2025.

1

Global framework and strategy to build and sustain leprosy capacity

- Global framework in place
- Comprehensive strategy in operation, normally in integrated Skin NTD context, in > 10 countries

2

Globally consistent leprosy data standards and data collection methodologies, leading to accurate reporting for improved programme planning and monitoring

- Initiatives piloted towards more accurate new case data
- Effective, integrated surveillance systems
- Widespread digital case-based data reporting
- Accurate records of patients with disabilities and/or at-risk

3

Readily available services related to mental wellbeing in leprosy

- Use of ILEP guides on stigma/mental wellbeing
- Access to point-of-care and referral services for mental wellbeing

4

Active engagement by persons affected by leprosy

- Countries specifically including leprosy in national human rights frameworks: target > 20
- 50% reduction in discriminatory laws
- National organisations representing persons affected by leprosy: target > 30
- Regular monitoring of stigma levels in countries

5

Innovative approaches through research, proof of concept, and application of game-changing technologies and processes

- ILEP Research strategy and priorities adopted
- Collaborative piloting/ proof of concept of new initiatives involving multiple ILEP Members

ENABLING ACTIONS

How the ILEP Federation aims collectively to achieve the key strategic goals

① Strong in-country collaboration between ILEP members | ② Sharing of knowledge and experience and putting into practice mutual learning | ③ ILEP Technical Commission outputs in line with key strategic goals | ④ Input through ILEP Advisory Panel into key strategic goals | ⑤ Effective advocacy within relevant forums of OHCHR and WHO | ⑥ Engagement in the work of the UN Special Rapporteur | ⑦ Increased understanding and capacity in human rights across the ILEP federation.

Programmatic highlights 2024

ILEP's vision is a world free from leprosy. Our mission is to work together towards zero transmission of leprosy, zero leprosy-related disability and zero exclusion. ILEP member associations work individually and collaboratively across a very wide range of programme activities towards this 'triple zero' endpoint.

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ILEP and its members published a comprehensive set of strategies that low-endemic countries can use to totally eliminate leprosy disease.

Towards zero transmission of leprosy

Leprosy is one of three neglected tropical diseases targeted by the World Health Organization (WHO) for interruption of transmission by 2030.

The slow downward trend in reported new case numbers over the 15 years is a matter of concern, as factors such as dwindling leprosy expertise, other health priorities and lack of political commitment present severe obstacles. However, child cases have halved in that period, and this is strong and welcome evidence of decreasing transmission of the bacillus that causes this disease. WHO urges countries to continue working towards interrupting leprosy transmission, particularly by investing in active case-finding and contact tracing with post-exposure prophylaxis.

During 2024, ILEP and its member associations:

- Provided technical expertise to governments, WHO (including through its Technical Advisory Group), the Global Partnership for Zero Leprosy (GPZL) and partners in many endemic countries.
- Appointed a new ILEP Technical Commission, consisting of eight technical subject-matter experts, and approved its workplan for the coming period. The workplan centres around knowledge gaps where new or updated technical guidance is needed.
- Supported government health programmes to build capacity in leprosy, at multiple levels in their health systems.
- Were active participants in the Leprosy Zero Transmission Symposium, under the auspices of the Global Partnership for Zero Leprosy, ten years after the first such symposium.

- Engaged in a wide variety of leprosy research programmes, through dedicated research facilities, long-term research projects, operational research, and participation in the Leprosy Research Initiative; and were active participants in LRI's in-person knowledge exchange.
- Used social media and other advocacy opportunities to spread ILEP's Beat Leprosy message for World Leprosy Day 2024.
- Published in Leprosy Review a comprehensive set of strategies that low-endemic countries can use to totally eliminate leprosy disease.
- Took available opportunities to advocate with countries to use the powerful tools provided under WHO's Leprosy Elimination Framework, published in 2023.
- Continued to follow up on gaps in the supply of drugs for leprosy treatment, and to press WHO for improvements in the order management and reporting system.
- Assisted governments in reporting leprosy data both for internal decision-making purposes and for inclusion in WHO's annual Global Leprosy Update.
- Developed standard operating procedures for active leprosy case detection, ready for publication in 2025.
- Reviewed WHO's leprosy training modules and supported the Lift Leprosy Learning project with technical advice.

ILEP members equip people to develop new livelihoods if the risk or reality of physical damage has meant that their previous work cannot be safely continued.

Towards zero leprosy-related disability

The disabling consequences of leprosy represent a very high cost to individuals, families and communities, and are thought to affect the lives of at least 3-4 million people alive today.

WHO emphasises the need for ready access to comprehensive, well-organised referral facilities where these consequences can be managed, and where patients can be encouraged and supported into self-care habits and lifestyle modifications designed to prevent further injury. But national referral systems are often weak or not easily accessible by the people that need them, and many countries look to ILEP members to tackle the ongoing physical, mental, social and economic repercussions of leprosy.

During 2024, ILEP and its member associations:

- Strengthened national health systems through the provision or support of leprosy referral services, such as specialist hospitals. Typically, these facilities can manage leprosy-related complications, supply assistive devices, advise patients on self-care, and offer reconstructive surgery with associated physiotherapy services.
- Reviewed for quality and accuracy a set of 32 published materials, from several countries, providing information for new patients on self-care and prevention of disability, and prepared for publication a reference list of recommended resources and best practices.
- Supported the formation of self-care and self-help groups and participated in ‘UPLIFT’, a major ILEP-funded project exploring best practices in community-based groups.
- Participated in a workgroup developing a WHO technical guide, published in early 2025, on the use of adaptive technologies for the benefit of persons with physical impairments caused by leprosy.
- Equipped people to develop new livelihoods if the risk or reality of physical damage has meant that their previous work cannot be safely continued.
- Undertook a comprehensive rewrite of ILEP’s Learning Guides on managing reactions in leprosy and preventing disability in leprosy, for publication in 2025.
- Were involved in workgroups of the International Disability and Development Consortium (IDDC) focusing on inclusive health, community-based inclusive development, inclusive safeguarding, and partnerships with organisations of persons with disabilities.
- Were active participants in the multi-NTD disease management, disability and inclusion subgroup of the NTD NGO Network (NNN).
- Prepared for participation in the triennial Global Disability Summit, to be held in 2025.

ILEP collaborated with LexisNexis in its global search for discriminatory laws not previously identified by ILEP.

Towards zero leprosy-related exclusion

Negative, sometimes hateful, community and official attitudes to individuals and their family members, and the constant experiences of social exclusion, can be the most troubling and the most disabling consequences of leprosy.

More than 20 countries even keep laws or regulations in force that discriminate against persons affected by leprosy. In theory there are protections against discrimination through, for example, the United Nations Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members, but these are seldom incorporated into countries' human rights protection frameworks.

During 2024, ILEP and its member associations:

- Embraced opportunities for engagement with the newly appointed UN Special Rapporteur for leprosy, including active support for her yearly reports to the UN General Assembly and the UN Human Rights Council.
- Continued to catalogue discriminatory legislation in all countries, and engaged in advocacy towards the repeal or amendment of these laws in several jurisdictions.
- Enabled persons affected by leprosy and other NTDs to make a powerful case at the NNN 2024 Conference for their inclusion in leprosy and NTD research activities.
- Completed and continued to advocate for use of the innovative NTD Inclusion Score Card, which organizations can use to self-assess their inclusiveness of individuals with lived experience of leprosy.
- Supported the ILEP Advisory Panel to undertake an in-person visit to Ethiopia, where it interacted intensively with the people's organization ENAPAL and with ILEP members and other NGOs working in leprosy.
- Provided initial input on the revision of the WHO Guide on participation of persons affected by leprosy, published in 2012.
- Advocated with the organizers of the 2025 International Leprosy Congress for participation of persons affected by leprosy on the organizing committees and for a major rebate in registration fees applicable to them.
- Participated in the newly formed workgroup of the Global Partnership for Zero Leprosy, focused on ensuring activities are people-centred.
- Collaborated with LexisNexis in its global search for discriminatory laws not previously identified by ILEP, resulting in 14 additional laws or regulations being recorded.

PHOTO: *Dalamar works tirelessly, often picking three times the daily quota of tea leaves to provide for her family.* © Ruth Towell

> *"As the disease was diagnosed early and I got the treatment early, I can work, and I can also play with my grandchildren."*

CASE STUDY: DALAMAR'S STORY

Dalamar, a 50-year-old tea picker from a tea estate in Bangladesh, faced a life-changing moment when she was diagnosed with leprosy during a skin camp at her local health clinic.

She had suspected that the numb patches on her skin might be leprosy – she had heard that it was spreading in the tea gardens – and she wanted to get treatment to protect her family. Despite this, her diagnosis initially filled her with fear. She couldn't understand why this was happening to her. Dalamar is the main earner for her family, and she worried about the implications for her family's wellbeing. She works tirelessly, often picking three times the required daily quota of tea leaves to provide for her family, which includes her husband, who is unable to work due to a hip injury, and her sons.

The timely diagnosis of leprosy allowed Dalamar to begin treatment early, preventing severe complications. The disease had not progressed enough for her to lose the feeling in her hands and feet due to nerve damage. She received Multi Drug Therapy and continued working, thankful for her ability to support her family and maintain her role in the community. Dalamar's story is one of resilience and community spirit; she and her friends in the tea gardens share food, support each other during work, and find joy even in challenging circumstances.

Dalamar's hopes for the future are simple yet profound: she dreams of her children having good relationships and her grandchildren receiving a good education and better job opportunities. She is optimistic about her treatment and her ability to continue providing for her family. Dalamar's story highlights the importance of early diagnosis and treatment in managing leprosy and the vital role of community support in overcoming the challenges posed by the disease.

First published by ILEP member The Leprosy Mission and used with permission.

Our mission is to work together to stop leprosy, to prevent disability and break the stigma resulting from leprosy.

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Game-changing collaborative projects

The CapaBle research project on blended learning, funded by the Leprosy Research Initiative, commenced in India and Nigeria.

In 2022, following adoption of a new five-year strategy, ILEP began work on four collaborative projects at a total budget of more than CHF 800,000, to produce potentially game-changing solutions so some of the major global challenges in leprosy.

The emphasis is on global impact and collaboration, so each project involves multiple ILEP member associations, and features initial multi-country piloting leading, if successful, to global scale-up. A fifth project, focusing on the new potential drug Telacebec, started in 2024.

Lift Leprosy Learning

Responding to worldwide concerns about the ongoing erosion in leprosy expertise, this project promotes a coordinated approach to leprosy capacity building. During 2024 the project moved forward strongly in advocating in multiple forums for coordinated capacity building and a structured approach to blended learning – a combination of web-based and hands-on training. The new hosting arrangement was launched on the InfoNTD platform, four new courses were developed and made publicly available, and the CapaBle research project on blended learning, funded by the Leprosy Research Initiative, commenced in India and Nigeria. By the end of 2024, it became clear that the allocated funds would not be enough to complete the project, and a case has been made to ILEP members for its continuance.

Global Leprosy Mapping Initiative

Responding to WHO’s call for standardised mapping to enable a detailed view of disease epidemiology and progression, this project analyses where countries are in terms of leprosy data collection and management, and provides tools and standardised approaches for improved mapping and better-informed decision making. During 2024, the tools developed in 2023 were put into active use initially in three of the intended twelve pilot countries (Nepal, Bolivia, and Senegal) and then also in Ethiopia. Typically, the project collects and analyses multi-year leprosy data from high-prevalence zones with the aim of improving early detection, targeted interventions, and surveillance efforts through integrating mapping with the national health data system. Outputs include up-to-date, comprehensive, leprosy maps that are valuable tools for policymakers and health organizations. Priorities for 2025 include support to countries in applying the Leprosy Elimination Monitoring Tool (LEMT) and integrating its mapping functions with the project’s mapping activities.

ILEP members committed USD 250,000 towards preclinical studies into the efficacy of Telacebec, a very promising candidate drug for both leprosy treatment and leprosy prevention.

From Words to Action

Reflecting the priority ILEP places on active engagement by persons affected by leprosy, this completed project has developed, piloted and launched the NTD Inclusion Score Card. This well-tested tool enables organisations to honestly assess where they stand in terms of the participation by persons affected by leprosy and other NTDs in their programmes and decisions. During 2024, ILEP member Deutsche Lepra- und Tuberkulosehilfe was able to share with other ILEP members the many positive learnings that had come from its global implementation of the Score Card. The tool was also promoted at a session of the NTDs NGO Network (NNN) conference. ILEP has committed to continuing to advocate for its widespread adoption and use in the leprosy and NTD worlds and, by extension, with NGOs that work in partnership with organisations of persons with disabilities.

UPLIFT

Reflecting ILEP's priorities around the empowerment, self-determination and mental wellbeing of persons affected by leprosy, this project researches success factors for community-based groups (CBGs) such as self-care groups and self-help groups. The goal is a harmonised model that integrates self-care, self-support and self-help practices with a clear focus on mental wellbeing. During 2024, the newly formed community groups in Bangladesh completed sections 1 and 2 of the completed CBG manual and are ready to move to the final section. The project has managed to navigate the delays caused by government re-structuring in Ethiopia, which resulted in turnover of CBG facilitators and the need to train new personnel, and political instability in Bangladesh in 2024, which caused several months' delay in the training of healthcare workers.

Telacebec

In 2024, a group of ILEP members, headed by ILEP member Fondation Raoul Follereau, committed USD 250,000 towards preclinical studies into the efficacy of Telacebec, a very promising candidate drug for both leprosy treatment and leprosy prevention. The studies are being managed by the TB Alliance, which owns the rights to Telacebec, and involves work at three separate laboratories. The ILEP Secretariat supported with review of the contract with TB Alliance and design of the intra-ILEP funding agreements. The preclinical studies are an essential contribution towards a multi-year clinical study into Telacebec in leprosy and Buruli ulcer, to start from 2026 with funding from EDCTP.

CASE STUDY:
NAKASI'S STORY

Nakasi lives in a remote village in the South Kivu province of DR Congo. Her life changed when she was 30 and she noticed some unusual spots on her skin.

Diagnosed with leprosy, she was initially admitted to hospital and subsequently put onto the regular 12-month multi-drug therapy treatment. Nakasi's husband had already been diagnosed with leprosy and so she did not face discrimination within her family. However, her community began to treat Nakasi differently. They wouldn't allow her to fetch water from the stream running right below her house, although she had always done that before. Likewise, she was not allowed to do the washing in the stream, but instead had to go down the mountain a few kilometres away to wash the clothes. This discrimination went on during the entire time of her treatment. Nakasi kept wondering "When will this discrimination come to an end?"

When the staff from ILEP member The Leprosy Mission made house calls, the neighbours started to realise that maybe leprosy wasn't as contagious as they had thought. As the staff explained to them that Nakasi no longer was contagious, they started to slowly rethink, even if it took more than a year before Nakasi was allowed to use the water from the stream.

The Leprosy Mission started a self-help group, consisting of 12 members to provide microloans. That way she could get a loan of 5 dollars to start up her selling of firewood. Nakasi collected the firewood locally and then sold it in Bukavu, the nearest city. Since then, Nakasi has used her entrepreneurial spirit to provide for her family and find new ways to bring in money, even after her husband died. Her dream is a better life than she has had, for her grandchildren.

First published by ILEP member The Leprosy Mission and used with permission.

> ***"When will all this discrimination come to an end?"***

PHOTO: *Nakasi's dream is a better life than she has had, for her twenty grandchildren.*

ILEP statement of commitment to the participation of persons affected by leprosy

The involvement of communities and persons affected is not a new concept in primary health care and disease programs. Human rights-based approaches to NTDs, including leprosy, emphasise that any interventions should be based on the principles of participation, non-discrimination and accountability. WHO has issued specific Guidelines for strengthening participation of persons affected by leprosy in leprosy services. However, the active participation of persons affected by leprosy is not always a reality.

THE EASI STRATEGY

Engaging persons affected by leprosy is essential to the success of leprosy programs. Having experienced the disease, disability and associated discrimination, they have a unique voice and perspective, they bring passion to the work and take the programs closer to the communities they are designed to benefit. ILEP and its Members adopt the EASI strategy to ensure that persons affected by leprosy have the space and the support for meaningful and effective participation.

EDUCATE
Human Rights
Build Capacity
Self-Representation
Decision Making

ADDRESS/REMOVE BARRIERS
Physical
Institutional
Attitudinal

SUPPORT
Self-Organization
Ability to Influence
Transformation
Change

INCLUDE
In Program Activities
In Decision Making
Their Contributions

ILEP COMMITMENT

In relation to the EASI strategy, and within their sphere of influence, ILEP and its Member associations commit to work towards the following outcomes:

- **Policy-making**: Persons affected by leprosy are supported to participate in the development, monitoring and evaluation of leprosy-related policies, guidelines and preferred practices at all levels.
- **Programs**: Persons affected by leprosy systematically participate in all stages of leprosy programs from planning, to implementation, monitoring and evaluation. Their knowledge, skills, experience and connections are valued in these roles.
- **Leadership, networking and sharing**: Persons affected by leprosy are supported to take on leadership roles in self-care groups, support groups and other relevant local, national and international networks; to seek resources and build local capacity; to encourage participation of new members; and to share their experience with others.
- **Advocacy**: Persons affected by leprosy actively participate in advocacy for participation of persons affected, human rights, the removal of all discriminatory laws, regulations and practices and universal access to quality services that are fully integrated into strengthened local health systems.
- **Public representation**: Persons affected by leprosy are supported to actively participate at local, regional and global fora and to become spokespersons in leprosy and related campaigns or speakers at public events.
- **Research**: Persons affected by leprosy are supported to participate in the planning and execution of leprosy-related research.
- **Gender**: Specific attention is paid to ensuring equal participation by women affected by leprosy in each of these actions.

Financial Highlights 2024

The income and expenditure highlights on this page are in Swiss francs (CHF). The audited financial reports are available on request.

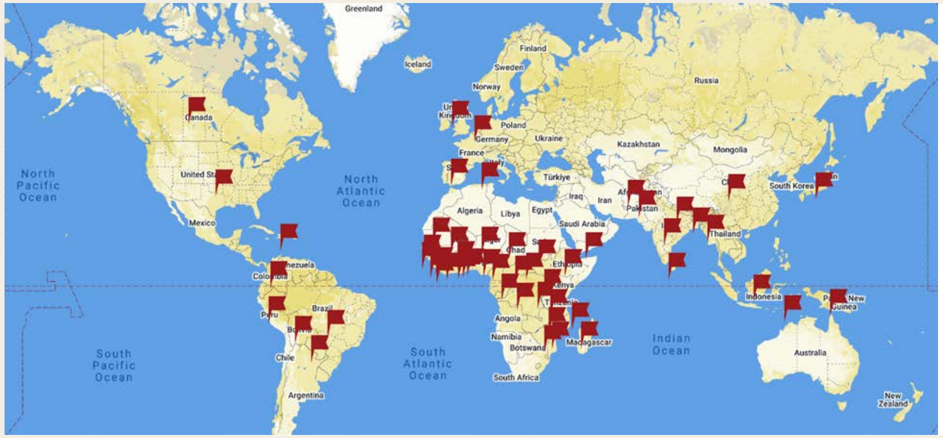
	2024	2023
Staff costs	131,569	118,016
Services from third parties	111,003	98,323
Office rent	3,563	5,616
Administrative expenses	15,059	13,305
Comms, memberships and IT expenses	8,776	10,493
Travel and meeting costs	71,044	57,679
Total expenditure	**CHF 341,014**	**CHF 303,432**
Membership contributions	303,336	301,790
Other income	5,912	629
Total income	**CHF 309,248**	**CHF 302,419**
Financial result	**CHF -31,764**	**CHF -1,013**

In addition, ILEP Members contributed CHF 103,478 (2023: CHF 142,987) towards the operation of the Global Partnership for Zero Leprosy.

ILEP MEMBERS

ILEP is a consortium of international non-government organisations (NGOs) with a shared desire to see an end to leprosy, and an acknowledgment that none of us can achieve this on our own.

Through mutual collaboration and partnership with others, we will achieve our ultimate goal of a world free from leprosy.



For a fuller picture of where ILEP Members work, see www.ilepfederation.org

Associazione Italiana Amici di Raoul Follereau

Damien Foundation Belgium

Deutsche Lepra- und Tuberkulosehilfe | German Leprosy and TB Relief Association

Effect Hope

FAIRMED

Fondation Raoul Follereau

Fontilles

Hope Rises International

Leprosy Relief Canada | Secours Lèpre

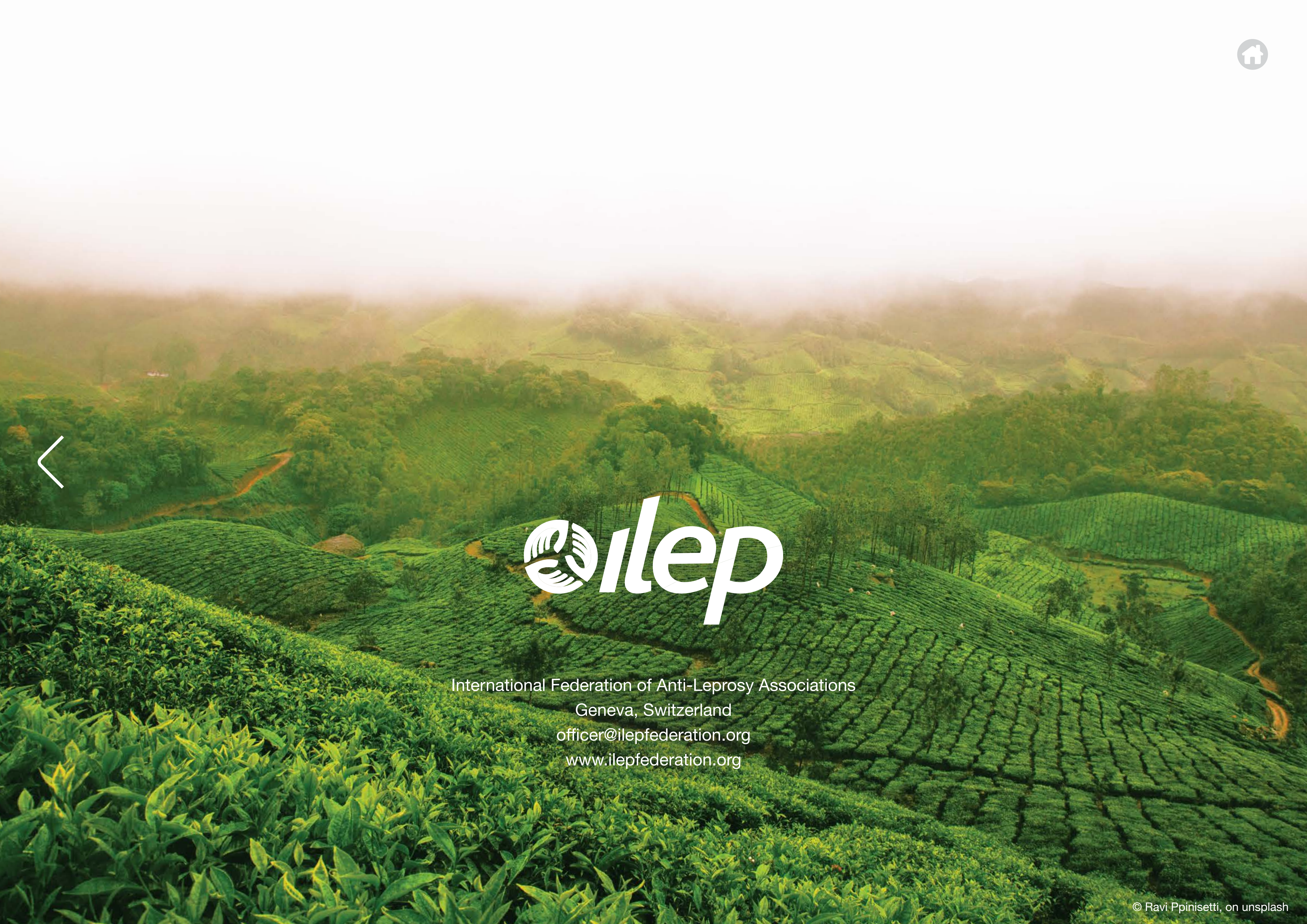
Lepra

NLR | Until No Leprosy Remains

St Francis Leprosy Guild

Sasakawa Health Foundation

The Leprosy Mission International



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