ilep

Working together towards a world free from leprosy

ILEP ANNUAL REPORT 2022

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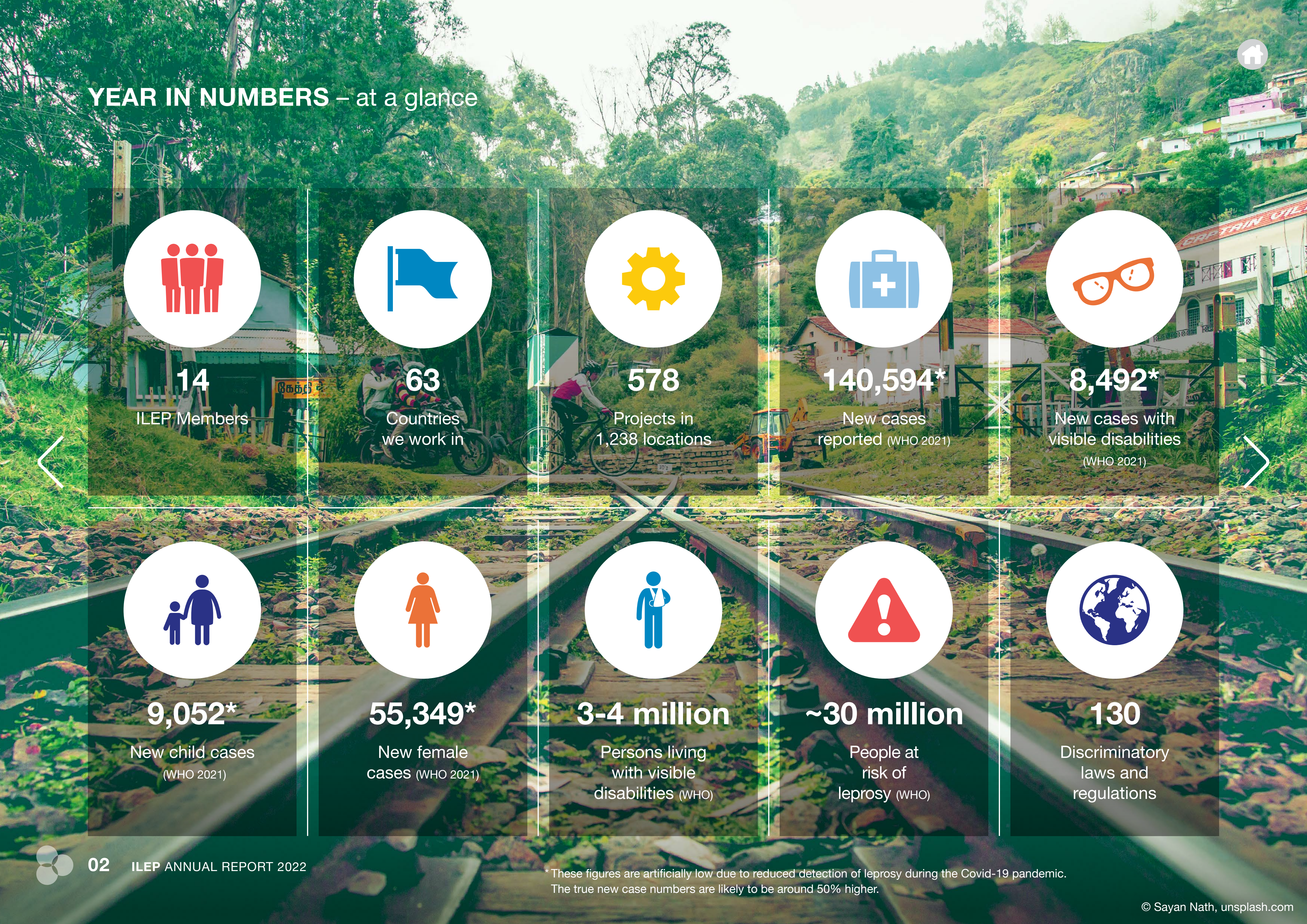
YEAR IN NUMBERS – at a glance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14
ILEP Members

63
Countries
we work in

578
Projects in
1,238 locations

140,594*
New cases
reported (WHO 2021)

8,492*
New cases with
visible disabilities
(WHO 2021)

9,052*
New child cases
(WHO 2021)

55,349*
New female
cases (WHO 2021)

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

~30 million
People at
risk of
leprosy (WHO)

130
Discriminatory
laws and
regulations

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* These figures are artificially low due to reduced detection of leprosy during the Covid-19 pandemic. The true new case numbers are likely to be around 50% higher.

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

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PRESIDENT'S REPORT

Brent Morgan, ILEP President

Game-changing collaboration

> **"ILEP launches four major collaborative initiatives in line with the 2021-2025 strategy."**

ILEP members relished the opportunity to meet in person twice this year, after almost three years of virtual meetings due to Covid-19. The second in-person meeting took place in Hyderabad in November. This coincided with the International Leprosy Congress, in which personnel from ILEP members and partners were a strong presence. Being in India, we took the opportunity for a very beneficial half-day interaction between the ILEP member CEOs and their team leaders in India, and also met the most senior director responsible for leprosy within the Ministry of Health and Family Welfare.

Early in 2022, ILEP called for concept notes for potentially game-changing projects to be funded from ILEP's Project Reserve. Proposals were scored against criteria such as alignment with ILEP's strategy, the significance of the challenge they addressed, innovation, potential global impact, value for money, involvement of multiple ILEP members, and participation of persons affected by leprosy.

Selecting from these proposals, in June ILEP launched four major collaborative initiatives in line with the 2021-2025 strategy. These initiatives are financed by CHF 500,000 from the ILEP Project Reserve combined with additional contributions from member associations. More detail can be found in this Annual Report on these projects and their expected impact. This opportunity for financial and programmatic collaboration towards ground-breaking objectives was inspiring to all member CEOs.

Also in June, the members decided to form multi-agency working groups to operationalise each of the five ILEP strategic goals within our 2021-2025 strategy. After some preliminaries in 2022, we are expecting these groups to operate actively in 2023. ILEP members recognise that the strategic outcomes that we aspire to can be achieved only with the active collaboration of all ILEP members, at both global and country level.

Brent

MESSAGE FROM THE CEO

Geoff Warne

Learning together, working together

> **“Virtual ILEP conferences are gaining far more diverse participation and, consequently, better outcomes.”**

The World Health Organization lists the erosion of leprosy expertise, at all levels, as one of the greatest challenges to the vision of a world free from leprosy. One of ILEP’s key strategic goals for 2021-2025 is to develop a global framework and strategy to build and sustain leprosy capacity. Many ILEP member associations have programmes to enhance leprosy knowledge and skills in the countries where they work, and also to ensure that leprosy knowhow is maintained in their own organisations.

Every second year, ILEP holds an international conference in which people share knowledge and expertise on topical issues important to them. Before 2020, these were relatively small in-person events, but we have found that virtual conferences are gaining far more diverse participation and, consequently, better outcomes. The March 2022 conference, in French and English, focused on ILEP’s role in active case-finding and health system strengthening. More than 250 people participated, 75% of whom were from 33 leprosy-endemic countries. The findings have been published in *Leprosy Review* and will be used by member associations, and partners, to boost their programme effectiveness.

The conferences not only build knowledge on good practice. They also help to build relationships and to increase appetite for working in partnership. Over recent years, there is a steady increase in the number of projects in which ILEP member associations are working together, sharing not only costs but also their distinctive areas of expertise. Other initiatives, such as the four game-changing projects approved by member CEOs in 2022 and the call for innovative project concepts for assessment in 2023, are helping to ‘normalise’ programme collaboration across multiple ILEP members. Considering the size of the challenges on the road to zero leprosy, we expect that multi-layered collaboration will be an ongoing theme for ILEP members and partners.

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.

Image: © Ruth Towell

Programmatic highlights 2022

ILEP's vision is a world free from leprosy. Our shared 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.

ILEP member associations were a very significant presence at the triennial International Leprosy Congress.

Towards zero transmission of leprosy

The very slight downward trend in reported new case numbers over the past decade is a matter of concern for all stakeholders striving to reach zero leprosy.

The World Health Organization (WHO) urges countries to work towards interrupting leprosy transmission by investing in active case-finding, contact tracing and other measures aimed at preventing the disease. But factors such as dwindling leprosy expertise, other health priorities and lack of political commitment present severe obstacles.

The sharp reduction in leprosy diagnosis and treatment during the Covid pandemic has resulted in an estimated backlog of 140,000 undiagnosed patients, who are at risk of disabling consequences and a potential route of infection to family and close contacts.

During 2022, 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. The ILEP Technical Commission, which consists of eight technical subject-matter experts, progressed its workplan comprising issues where new or updated technical guidance is needed.
- Supported government health programmes to build capacity in leprosy. One innovative approach was a two-week South-South intensive advanced leprosy training and exchange.
- Analysed the newly published WHO Skin-NTDs Strategic Framework, participated in a conference on skin-NTD integration in Africa, and supported WHO's planning for a global skin-NTDs meeting in 2023.
- Were a very significant presence at the triennial International Leprosy Congress held in Hyderabad, India, of which ILEP was one of the official partners.

ILEP members supported governments to scale up active case-finding, reflecting global concerns about the large post-Covid backlog in undetected and untreated leprosy.

- Supported governments to scale up active case-finding, reflecting global concerns about the large post-Covid backlog in undetected and untreated leprosy.
- Engaged in a wide variety of leprosy research programs, through dedicated research facilities, specific long-term research projects, operational research, and participation in the Leprosy Research Initiative which is co-funded by some ILEP members.
- Attended the annual NGO NTDs Network (NNN) conference. This included a very well-attended half-day workshop on the challenges and opportunities around integration of leprosy with other NTDs, and the implications of the forthcoming WHO guidance for countries wishing to assert leprosy elimination (defined as interruption of transmission).
- Co-developed and promulgated a factsheet on post-exposure prophylaxis in leprosy.
- Continued to monitor the supply of drugs for leprosy treatment, and issued an advisory bulletin on suppliers of rifampicin for post-exposure prophylaxis.
- Evaluated, and in some cases endorsed, the Kigali Declaration on NTDs.
- Participated in the ongoing work of GPZL, including country reviews, roadmaps and action plans, and in the working groups of the NNN network.
- Assisted governments in reporting leprosy data both for internal decision-making purposes and for inclusion in WHO's annual Global Leprosy Update.
- Held an ILEP virtual conference of around 250 people on the topics of active case-finding and health system strengthening, and published the findings in *Leprosy Review.*

Self-help groups can have a powerful effect in encouraging solidarity and also enabling new livelihoods through small savings and loan schemes.

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 most countries are doing little to tackle the ongoing physical, mental, social and economic repercussions of leprosy.

During 2022, 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.
- Supported the formation of community self-care groups, and self-help groups that can have a powerful effect in encouraging solidarity and also enabling new livelihoods through small savings and loan schemes.
- Co-developed and promulgated a factsheet on how to classify and manage leprosy reactions.
- Participated in the Global Disability Summit, in which ILEP lodged its own statement of commitments to the rights of persons experiencing disability through leprosy.
- Equipped people to develop new livelihoods if the risk or reality of physical damage means that their previous work cannot continue.
- Worked in association with community-based organisations of persons with disabilities, seeking the participation of persons affected by leprosy in these organisations.
- Were involved in workgroups of the International Disability and Development Consortium (IDDC) with its focus on inclusive development.
- Celebrating the award of the NTD Innovation Prize to an ILEP member project that will scale up digitally based care for leprosy complications in 20 districts in Bangladesh.

ILEP and ILEP members engaged in advocacy towards the repeal or amendment of discriminatory laws in several jurisdictions.

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 discriminatory laws in force 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 2022, ILEP and its member associations:

- Engaged through the ILEP Advisory Panel, which consists of seven people with first-hand experience of leprosy, in dialogue with national organisations of persons affected by leprosy and also the Global Forum of people's organisations, organised by one of the ILEP members.
- Supported the mandate of Alice Cruz, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. Practical aspects of support included providing information and evidence for her reports to the Human Rights Council and the UN General Assembly. In 2022, these reports were respectively about the right to health and the need for national legal protections for the rights of persons affected by leprosy.
- Continued to catalogue discriminatory legislation in all countries, and engaged in advocacy towards the repeal or amendment of these laws in several jurisdictions.
- Helped PerMaTa, a people's organisation in Indonesia, to produce a top-quality report to the Universal Periodic Review, a function of the UN Human Rights Council, recommending government action for attainment of their rights by persons affected by leprosy.
- Publicised World Leprosy Day and World NTD Day around the theme 'United for Dignity'.
- Printed and distributed ILEP's Statement on Participation by persons affected by leprosy, at the NNN Conference and International Leprosy Congress. A copy of the Statement can be read in this Annual Report.

CASE STUDY: ÉLODIE’S STORY

Élodie is from Kongo Central, a province to the far west of the Democratic Republic of the Congo. She was diagnosed with leprosy in 2009 when she developed patches on her back and started to find it hard to pick things up.

She was finding it very difficult to work. She was provided with the cure for leprosy, a combination of three antibiotics known as multi-drug therapy (MDT). One of the antibiotics included in MDT can darken the colour of your skin and Élodie’s skin went very black, which made her so embarrassed that she stayed home. She felt stigmatised by the other people in her community.

In 2012, Élodie started to experience leprosy reaction, a painful consequence of leprosy that made it feel like her hands were burning. This carried on for three years. Sadly, during these years Élodie’s husband left her and remarried. He left her with their five children and died of malaria shortly afterwards.

“I stayed in the house alone and felt so sad. I was very anxious and got very high blood pressure. Life was very hard for me, I had to feed my children, and no one from my husband’s family would help. This is still the case.”

Élodie received advocacy training from an organisation called OPALCO (Organisation des Personnes Affectées par la Lèpre au Congo) which is an organisation of persons affected by leprosy in DR Congo. Advocacy training supports people to speak out for their and their families’ rights, needs and entitlements and to convey accurate information about leprosy.

Thanks to this training and her continued engagement with OPALCO, Élodie is now the head of OPALCO for the whole of Kongo Central.

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PHOTO: *As provincial head of OPALCO, Élodie supports others grappling with the disabling and stigmatising effects of leprosy.* © Tom Bradley

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

Game-changing collaborative projects

The emphasis is on global impact and collaboration, so each project involves multiple ILEP member associations, with initial multi-country piloting leading, if successful, to global scale-up.

Over its 60-plus years, ILEP has regularly recalibrated its priorities and programmes in response to new thinking, new tools and changing needs and contexts.

In 2022, following adoption of a new five-year strategy, ILEP invited its members to propose project concepts that offered potentially game-changing solutions to some of the major global challenges in leprosy.

The member CEOs subsequently selected four collaborative projects, to be launched with funding from ILEP's Project Reserve with additional contributions from some ILEP members. The emphasis is on global impact and collaboration, so each project involves multiple ILEP member associations, with initial multi-country piloting leading, if successful, to global scale-up.

Lift Leprosy Learning

This project responds to worldwide concerns, expressed by WHO and many endemic countries, about the ongoing erosion in leprosy expertise, including clinical skills at all levels.

It will promote a coordinated approach to leprosy capacity building, usually in integrated settings, develop new and modernised training resources adaptable to varying contexts, propose contemporary learning approaches that are feasible and effective, and pilot these in seven countries.

The project reflects what ILEP sees as one of its roles, to apply innovative thinking in an effort to make progress towards resolving some of the very difficult operational problems in the leprosy world.

Global Leprosy Mapping Initiative

This project responds to the call in the WHO NTDs Roadmap for standardised mapping to give a detailed view of disease epidemiology and progression. This is especially important in leprosy because it is a clustered disease: uniform approaches to active case finding, for example, waste resources. Working with eleven pilot countries, the project will analyse where the countries are in terms of leprosy data collection, reporting, analysis and database management, and provide tools, guidance, and standardized approaches for improved mapping and better-informed decision making.

ILEP member associations recognise that through collaboration, co-operation and harnessing collective strength we will have a far greater impact in the fight against leprosy.

The project reflects what ILEP sees as one of its roles, to research best practices, help governments to identify how to apply those practices to their work, and support their scaling up so that they are part of the country's strategy, policy and standard operating procedures.

From Words to Action

This project reflects the priority ILEP places on active engagement by persons affected by leprosy. It builds on ILEP's formal Statement of Commitment to their participation. This statement, which is included in this Annual Report, was formulated by the ILEP Advisory Panel, which consists of seven people with personal experience of leprosy.

The project is to develop, pilot and launch the Inclusion Score Card, a tool for 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. When the Scorecard is fully developed and piloted, ILEP intends to advocate for its widespread adoption and use in the leprosy and NTD world.

UPLIFT

This project reflects ILEP's priorities around the empowerment, self-determination and mental wellbeing of persons affected by leprosy. Community-based groups, such as self-care groups and self-help groups, are known to have great potential to make leprosy a 'disease of no consequence', with no disability, no associated prejudice and no quality-of-life impact.

The project will research success factors for these groups, and develop a harmonised model that integrates self-care, self-support and self-help practices with a clear focus on mental wellbeing.

After piloting in three countries, ILEP intends to offer the completed work to governments, NGOs and civil society organisations – especially organisations of persons affected by leprosy – that are establishing community groups for empowerment, livelihoods, disability prevention and mental wellbeing.

Most of these four projects were initiated in the last quarter of 2022, and progress will be described in future ILEP Annual Reports.

CASE STUDY: VENKI'S STORY

Venki, a 19-year-old second year nursing student, comes from a leprosy colony in Andhra Pradesh, India. Her father had leprosy and HIV-AIDS and died when Venki was six years old. She is an only child and her mother is a homemaker and cultivates vegetables for a living.

The director of the Brighter Future Development Trust, a partner organisation of ILEP member The Leprosy Mission, visited Venki's colony where he met Venki's mother, and offered a place for Venki to stay and study. She moved into Rainbow Home when she was eight and lived there full-time until the age of 16.

The Home offered her training in computers, office work, public speaking and English language skills. When she became older, she helped the younger children in the Home, which instilled in her a passion for nursing. Rainbow Home worked hard to secure her a place in the leading medical college in the State, where she obtained a government seat by merit.

"My life and my future would have been fully damaged but for Rainbow Home. I wouldn't have been able to study. Now I am in a good college, doing a great course. Nursing has a lot of opportunities in India and abroad, so I want to explore those opportunities and earn well. My mother is very happy seeing me achieving these things, but she is lonely at home. So once I have a house, I will take her with me and will help and support her in her old age".

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PHOTO: *Overcoming the disadvantages of upbringing in a leprosy colony, Venki won a place in the best medical college in her state.* © The Leprosy Mission

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 2022

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

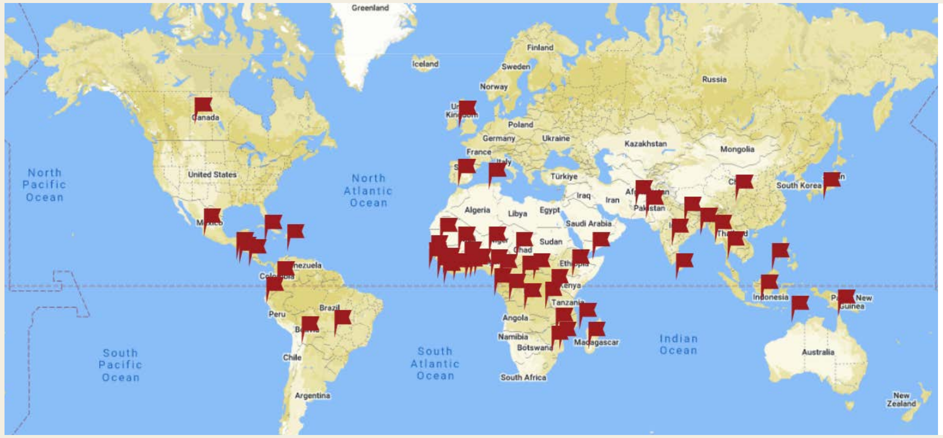
	2022	2021
Staff costs	111,648	95,253
Services from third parties	116,421	107,201
Office rent	4,089	3,891
Administrative expenses	15,236	12,085
Comms and IT expenses	10,745	10,091
Travel and meeting costs	89,398	-417
Financial expenses and Taxes	0	-2,500
Total expenditure	**CHF 347,537**	**CHF 225,604**
Membership contributions	303,548	298,519
Reimbursements and other income	596	0
Total income	**CHF 304,144**	**CHF 298,519**
Financial result	**CHF -43,393**	**CHF 72,915**

In addition, ILEP Members contributed CHF 309,782 (2021: CHF 318,557) towards the operation of the Global Partnership for Zero Leprosy.

ILEP MEMBERS

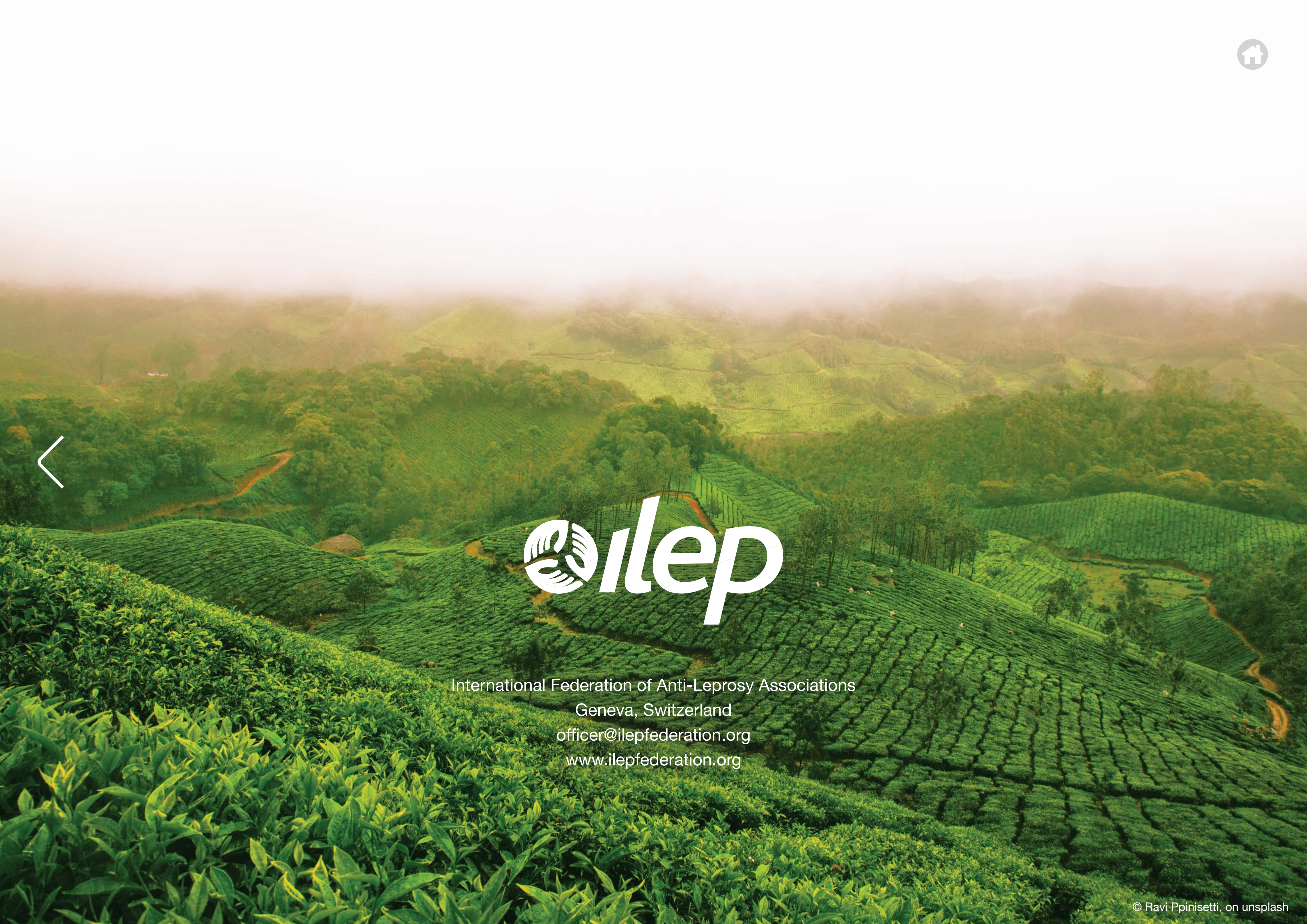
ILEP is a consortium of international non-government organisations (NGOs) with a shared desire to see an end to leprosy, and an acknowledgment that none of us can achieve this on our own.

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

- American Leprosy Missions
- 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
- Leprosy Relief Canada | Secours aux Lépreux
- Lepra
- NLR International
- St Francis Leprosy Guild
- Sasakawa Health Foundation
- The Leprosy Mission International



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International Federation of Anti-Leprosy Associations
Geneva, Switzerland
officer@ilepfederation.org
www.ilepfederation.org

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