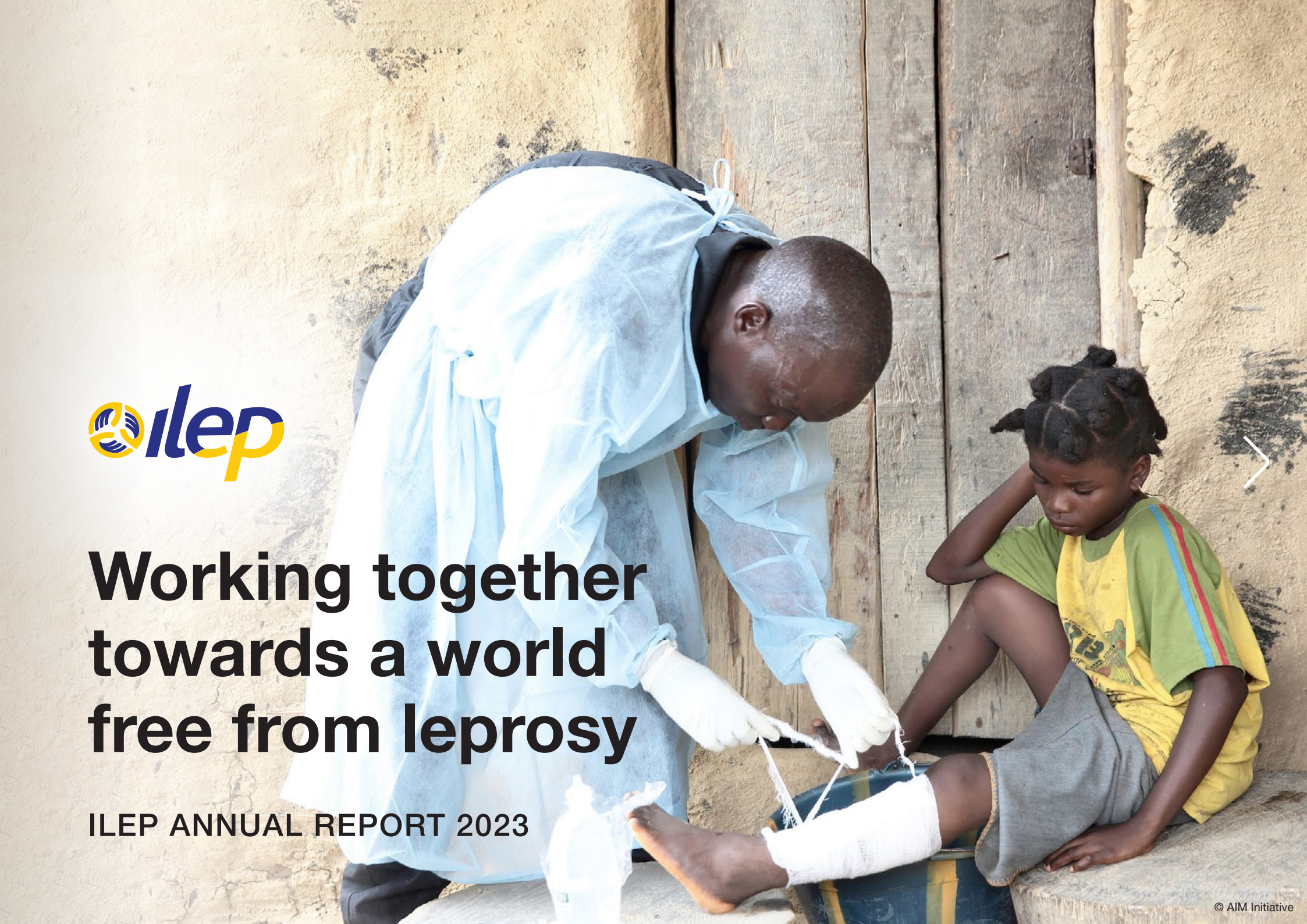

Working together towards a world free from leprosy

ILEP ANNUAL REPORT 2023

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YEAR IN NUMBERS – at a glance

14
ILEP Members

55
Countries we work in

598
Projects in 1,122 locations

174,087
New cases reported (WHO 2022)

9,554
New cases with visible disabilities (WHO 2022)

10,302
New child cases (WHO 2022)

67,657
New female cases (WHO 2022)

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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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

Towards leprosy elimination

"ILEP members have welcomed ground-breaking publications on interruption of transmission."

In 2023 we marked the 150th anniversary of Armauer Hansen's discovery of *Mycobacterium leprae*, the causative agent of leprosy or Hansen's disease. The bracing reality 150 years later is that, although leprosy has disappeared in some countries and is in slow decline worldwide, we are still some distance from 'Beating leprosy' – the theme of our latest World Leprosy Day campaign, and the touchstone of ILEP members' passion and energy worldwide.

Yet it was fitting that 2023 marked another significant moment for the leprosy world. In midyear, the World Health Organization launched its new technical guidance *Interruption of transmission and elimination of leprosy disease*. This followed three years of work by a task force which involved several ILEP member personnel and was led by the chair of the ILEP Technical Commission.

The new Leprosy Elimination Framework sets out the phases of elimination and the milestones that demonstrate when a country or sub-national area progresses through them.

Later in the year, ILEP member personnel worked with WHO and the government to confirm that the Maldives has achieved interruption of transmission of *M. leprae*, the first recently endemic country to do so.

There are many implications for ILEP and for the leprosy world as a whole. We anticipate that governments will call upon ILEP members to support their use of the new tools that examine trends at subnational level and give a more granular view of endemicity. Some of these requests will come from low-endemic countries that see an opportunity to seek formal WHO verification that they meet elimination criteria. In the process, we expect a growing belief among endemic nations that, with proper planning, adequate allocation of funds, training of staff and vigorous deployment of the available tools, they too can visualise an end to leprosy.

MESSAGE FROM THE CEO

Geoff Warne

The power of collaboration

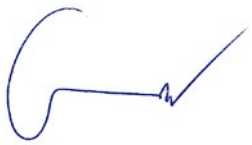
> **“Collaboration, cooperation and harnessing of collective strengths are part of ILEP’s DNA.”**

Collaboration, cooperation and harnessing of collective strengths are part of ILEP’s DNA. One of the core purposes when ILEP was founded was to ensure coordination in leprosy control worldwide. 60 years later, although the leprosy landscape is different, collaborative approaches are still essential to our joint impact towards zero leprosy.

Increasingly, this collaboration is both internal and external. ILEP holds regular workshops to explore how to work together more effectively and to discuss joint activity at country level. These workshops involve not only ILEP members but also the wide range of stakeholders active in leprosy: government representatives, organisations of persons affected by leprosy, other NGOs. By actively modelling cooperation, ILEP promotes an evolution towards national partnerships for zero leprosy through which stakeholders share expertise and resources into national zero leprosy roadmaps. Similarly, marking ten years since the founding of the Leprosy Research Initiative in 2013, we celebrate the fact that non-ILEP partners are enabling a greater pool of combined funding for crucial leprosy research.

ILEP is also engaged in global-level networks, with the object of advocacy and practical co-working towards shared zero-leprosy goals. In 2023 we took a lead in the restructuring and new strategy formation of the Global Partnership for Zero Leprosy, which ILEP co-founded in 2018. We remain active in the NTD NGO Network, ensuring that leprosy features strongly in its annual conferences. ILEP is in official relations with the World Health Organization and on that basis, we participate in both global and regional consultations. A highlight in 2023 was the inaugural WHO global meeting on skin NTDs, in which half of the 800 participants listed leprosy as a disease interest. ILEP also has consultative status with the UN Economic and Social Council.

The road to a world free from leprosy is a challenging one. ILEP will continue to strengthen existing partnerships and seek new collaborative opportunities towards that goal.



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: © Tom Bradley

Programmatic highlights 2023

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.

ILEP members supported governments to scale up active case-finding in response to the post-Covid backlog in undetected and untreated leprosy.

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 with post-exposure prophylaxis, 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.

During 2023, 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, continued its work on issues 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 WHO's inaugural global skin NTDs meeting, demonstrating shared commitment to integrated approaches in disease control.
- Supported governments to scale up active case-finding, especially in view of concerns about the post-Covid backlog in undetected and untreated leprosy.
- Participated in a working group of the Global Partnership for Zero Leprosy that resulted in adoption by WHO of two Target Product Profiles for leprosy diagnostic tests.

- 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, founded by ILEP members 10 years ago.
- Welcomed the publication of WHO's new technical guidance establishing the Leprosy Elimination Framework.
- Attended the annual NGO NTDs Network (NNN) conference, co-hosting a number of workshops and running a very well-attended half-day programme featuring the main themes of ILEP's Lift Leprosy Learning project.
- Continued to follow up on any evidence of gaps in the supply of drugs for leprosy treatment, and to push for coordinated supply of rifampicin for post-exposure prophylaxis.
- Advocated for rationalisation of WHO's guidance on anti-leprosy treatment for children under 10 and the supply of child-friendly drugs at the right dosages.
- Participated in the strategic refocusing of the Global Partnership for Zero Leprosy onto zero transmission, 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.

Through UPLIFT, a major ILEP-funded project, members are exploring best practices in community-based groups.

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 2023, 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 self-care and self-help groups and participated in 'UPLIFT', a major ILEP-funded project exploring best practices in community-based groups.
- Undertook a global survey on the in-country availability of essential leprosy reaction drugs.
- Participated in a global WHO consultation on assistive technologies in 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.
- 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) focusing on inclusive health, community-based inclusive development, inclusive safeguarding, and partnerships with organisations of persons with disabilities.
- Supported a constituency statement to the World Health Assembly urging Member States to champion health equity for persons with disabilities.

ILEP lobbied successfully for a further three-year term for the UN Special Rapporteur.

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 2023, ILEP and its member associations:

- Engaged through the ILEP Advisory Panel, which consists of seven people with personal experience of leprosy, in dialogue with national organisations of persons affected by leprosy and other NTDs, including a newly-formed pan-Africa consortium of people's organisations.
- Lobbied successfully for a further three-year term for the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.
- Embraced opportunities for engagement with the Special Rapporteur, including active support for her report on achievements during the first six years of the mandate and the daunting list of remaining challenges.
- Continued to catalogue discriminatory legislation in all countries, and engaged in advocacy towards the repeal or amendment of these laws in several jurisdictions.
- Publicised World Leprosy Day around the theme Act Now: End Leprosy, calling on governments, decision-makers, donors and the global health community to prioritise efforts to realise zero leprosy goals.
- Completed, demonstrated and widely publicised the innovative NTD Inclusion Score Card, aimed at enabling NGOs and partners to self-assess their inclusiveness of individuals with lived experience of leprosy and organisations that represent them.

CASE STUDY: BILKIS BEGUM'S STORY

Bilkis Begum is 48 years old and lives in the Bogura district of Bangladesh. She has three daughters and a son, but sadly her husband passed away shortly after the birth of her youngest daughter.

During a routine check-up when her daughter was one year old, her doctor noticed that she had patches of white skin which had very little sensation. She soon received a diagnosis of leprosy and was sent for multidrug therapy (MDT) treatment at the regional clinic. With no husband, no support from her wider family or community, and trying to feed four young children, Bilkis had no choice but to beg for food and money, forcing her to delay her treatment until her children were older.

The delay in treatment meant Bilkis' condition seriously deteriorated. Her legs became weak, and she lost significant sensation as a result of nerve damage. Unable to walk or maintain employment, she used a wheelchair to beg, which took a significant toll on her emotional wellbeing. Her children were taken into an orphanage, and she was isolated in her community.

The Bogura Federation, a grassroots organisation supported by Lepra, provides a sense of community, social and economic support for people affected by leprosy. It arranged for Bilkis to join Lepra's Mind to Heart project. Supported by a 'Mental Motivator', she joined counselling sessions to help her rebuild her confidence and sense of dignity. Government advocacy by Lepra and Bogura Federation helped her to receive vital economic support and suitable housing. She has become a champion in her community, a symbol of resilience, strength, and emotional recovery. Bilkis now plans, with the help of the Federation, to open her own small shop, selling groceries to provide a sustainable income for the future.

First published by ILEP member Lepra and used with permission.

PHOTO: *'Mind to heart' counselling sessions have helped Bilkis rebuild her confidence and sense of dignity.* © Tom Bradley

Bilkis has become a champion in her community, a symbol of resilience, strength, and emotional recovery.

Image: © The Leprosy Mission England and Wales

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

Game-changing collaborative projects

Each project involves multiple ILEP member associations, and features initial multi-country piloting.

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 to 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.

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 2023 the project moved forward strongly in advocating in multiple forums for coordinated capacity building. It has been developing an increasingly thorough repository of electronically available materials for blended learning, available on the InfoNTD platform. The Leprosy Research Initiative has approved funding towards the first piloting of the LLL concept and tools in Nigeria and India.

Global Leprosy Mapping Initiative

Responding to WHO's call for standardised mapping for a detailed view of disease epidemiology and progression, this project analyses where the 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 2023, the necessary tools were finalised and put into active use in the first three of the intended twelve pilot countries: Nepal, Bolivia, and Senegal.

The NTD Scorecard enables organisations to honestly assess where they stand in terms of participation.

From Words to Action

Reflecting the priority ILEP places on active engagement by persons affected by leprosy, this project – substantially completed during 2023 – 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.

ILEP has committed to advocating 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 2023, a global consultation (one of the project fundamentals) demonstrated the need to alter the design to include trained peer supporters for all the CBGs involved in the project. The team also worked on a manual for CBGs and began preparing for project implementation in Bangladesh, Ethiopia and India.

I lost hope. I thought with leprosy, I'll lose sensitivity and not be able to do anything with my life.

CASE STUDY: REMY'S STORY

Remy is 24 years old and is from DR Congo. He lives in a small leprosy settlement of just a few houses, built by the government in the 1980s for those affected by leprosy.

Remy was born here. He lives with his parents and two siblings. There are seven brothers and sisters in total, though four live away from home. He's the second youngest. His father, Fabien, is also affected by leprosy.

Remy finished high school and does various jobs at home – farming cassava, palm oil, and honey. It was in 2013 that he got the first symptoms of leprosy while studying at secondary school. Since his family were very familiar with leprosy, he was taken straight to the local hospital and diagnosed. "As I was born here, I know the disadvantage of leprosy, and I lost hope. I thought with this, I'll lose sensitivity and not be able to do anything with my life. I was fearful that it would eventually kill me."

He no longer thinks like this about leprosy, having been educated better. "When I started taking MDT (multi drug therapy, the antibiotics that cure leprosy) my skin went darker and dried up. But after two months my hands became strong again. They're still strong now."

Beekeeping was introduced in this small village in 2011 by The Leprosy Mission, and they are known for selling honey. The Leprosy Mission trained Remy and his father Fabien in beekeeping and provided them with beekeeping equipment, in particular the protective jacket, hat and gloves. There are 29 hives in total in the community and they sell the honey for $5 a litre.

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

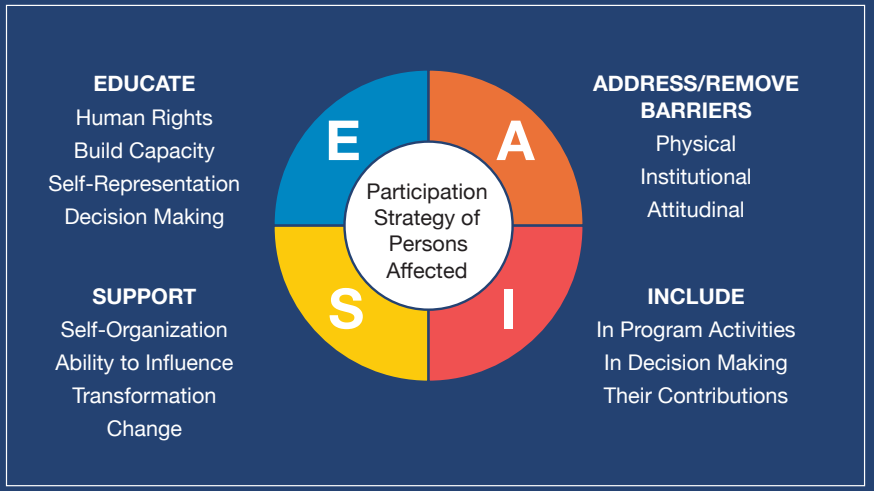
PHOTO: *'After two months my hands became strong again. They're still strong now.'* © Tom Bradley

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.



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 2023

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

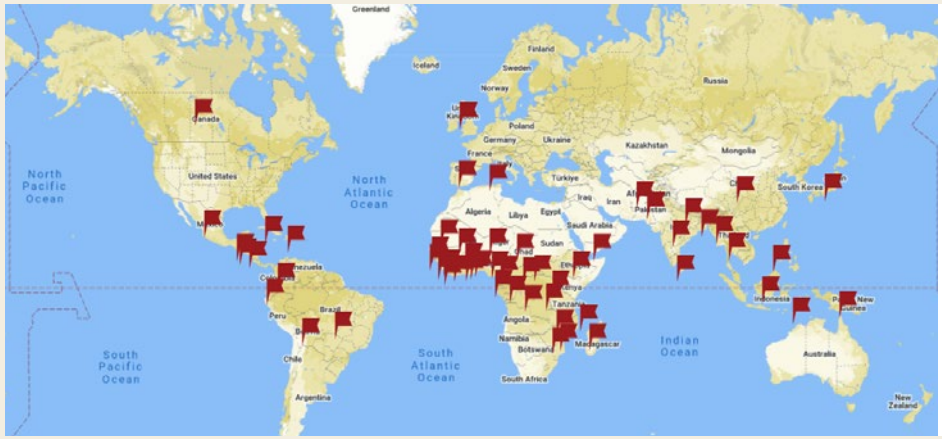
	2023	2022
Staff costs	118,016	111,648
Services from third parties	98,323	116,421
Office rent	5,616	4,089
Administrative expenses	13,305	15,236
Comms, memberships and IT expenses	10,493	10,745
Travel and meeting costs	57,679	89,398
Financial expenses and Taxes	0	0
Total expenditure	**CHF 303,432**	**CHF 347,537**
Membership contributions	301,790	303,548
Other income	629	596
Total income	**CHF 302,419**	**CHF 304,144**
Financial result	**CHF -1,013**	**CHF -43,393**

In addition, ILEP Members contributed CHF 142,987 (2022: CHF 309,782) 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.



ilep

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

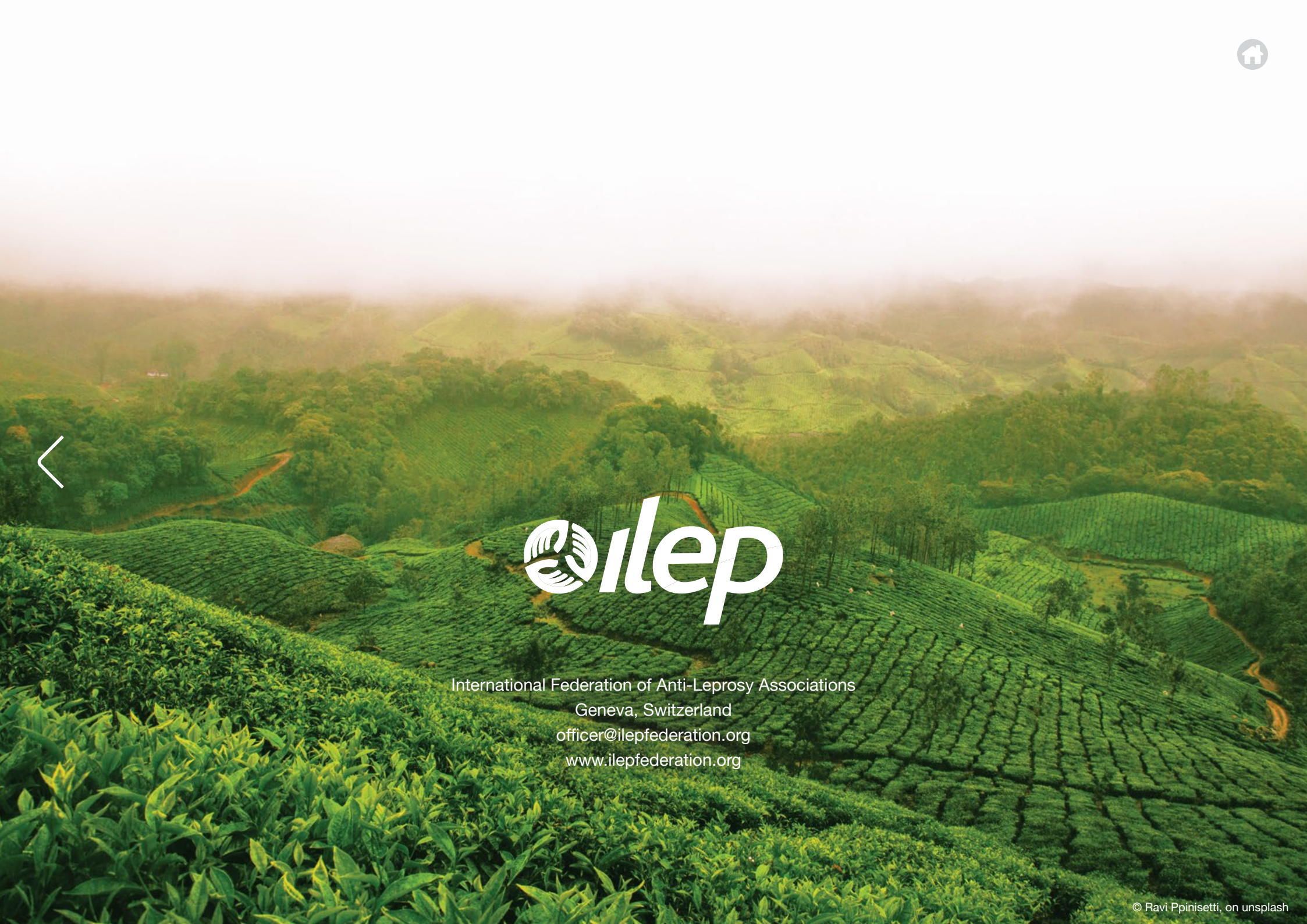
Lepra

NLR

St Francis Leprosy Guild

Sasakawa Health Foundation

The Leprosy Mission International



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

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