Working together to stop leprosy, to prevent disability and to break the stigma resulting from leprosy
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Front cover Rebahti Mahto and her daughter
President’s Overview of 2015

Welcome to the 2015 Annual Review. 2015 was a transformational year for ILEP.

ILEP underwent a major restructure at the governance, strategic and operational levels to become a more dynamic and mission-driven organisation. Marie Staunton, as interim Chief Executive at the start of the year, was instrumental in starting the journey of ILEP to a results-oriented, outward-facing Federation that is committed to working together to fight leprosy in partnership with others committed to this goal.

In March 2015, we closed the London office and opened the new ILEP Office in Geneva, to align more closely with the wider global health community and become more externally facing. In April 2015, we welcomed our new Chief Executive Officer, Tanya Wood.

I would like to thank Marie for her drive and inspiration for transforming ILEP. I would like to congratulate Tanya for the progress that she has made in the fine-tuning of ILEP’s new strategy and in building relationships with our strategic partners in leprosy, neglected tropical diseases and disability.

I would also like to thank our two advisory boards, ILEP’s Technical Commission, chaired by Professor Cairns Smith and the new Panel of women and men affected by leprosy for their important support and guidance throughout the year.

We can be particularly pleased by the momentum in the relationship with the World Health Organization and our participation in the NNN – the NTD NGDO Network – both relationships contributing to the success of our Enabling Action 2, Working with Others to help us achieve our Strategic Goals. See Strategy Summary on page 5 for more details.

Looking at ILEP as a symphony orchestra remains an inspiring exercise. We have managed to play a number of attractive tunes this year with several Members excelling on their instruments and ILEP coordinating these great contributions. Our major compositions are still works in progress in 2016, our anniversary year, a year to commemorate and look forward to. Our best anniversary present would be to make progress and break through the stagnant leprosy situation in many countries. The shared goal of a leprosy free world is a powerful source of inspiration to compose the symphony that will make it happen.

2016 will be a significant year. In ILEP’s 50th year, we will continue the work we have started in 2015, to see how we can work better together, how to support and develop our country level strategies and coordination, while finding better means of information sharing to realise the value of the Federation.

We will continue to work with others in support of these critical targets to achieve a world free of leprosy and support for those affected by this disease:

- Reduction of new leprosy cases with G2D to less than one case per million population
- Zero G2D among paediatric patients
- Zero countries with legislation allowing discrimination on the basis of leprosy

New Member

In the year of ILEP’s 50th anniversary, we are particularly pleased to welcome our new Member, the Ordre de Malte and look forward to working with our new colleagues.

I wish you a prosperous 2016 and happy 50th anniversary.

Jan van Berkel, President ILEP
Chief Executive Officer’s comments

Dear Colleagues

Thank you for a great welcome to ILEP. 2015 was an exciting year and I would like to thank the entire ILEP family for their support during this time.

Externally we saw the adoption of the SDGs with the critical inclusion of the target to end neglected tropical diseases by 2030 and significant references to disability inclusion in these new Goals, the new Global Leprosy Strategy spearheaded by WHO.

Internally, 2015 was a year of change for ILEP at the governance, strategic and operational levels. At the governance level, the newly formed Executive Board met regularly and we enjoyed two successful Members’ Assemblies that saw the approval of the constitution for the new Geneva office. ILEP’s governance will continue to be guided by our ITC and Panel of women and men affected by leprosy.

This is facilitated by our Enabling Actions of working better together, working better with others and raising the profile of leprosy. We also produced an operational strategy outlining the commitment of the ILEP Office in facilitating this. See Strategy Summary on page 5 for more details.

Operationally, we have started looking at our country level coordination, a key pillar of ILEP’s work and launched the three Working Groups to enable us to share better understanding of our respective work to really grow the strength of the Federation.

2016 we will make the approaches we have created in focusing on how we reach the global targets with better country level coordination, increased advocacy and better means of sharing evidence and learning within ILEP.

Tanya Wood, ILEP’s Chief Executive Officer

At the strategy level, thanks to the support of many ILEP Members and partners, we produced a new strategy, focussed on our Strategic Goals of stopping transmission, preventing disabilities and promoting inclusion.

A world free from leprosy

Enabling actions

Working more effectively together
Working more effectively with others
Increasing the profile of leprosy

Strategic objectives
Stopping transmission
Preventing disabilities
Promoting inclusion
ILEP strategy - summary

Our new strategy was developed in 2015, a critical year in the achievement of a world free of leprosy. The United Nations agreed new Sustainable Development Goals, WHO produced a new global leprosy strategy and ILEP underwent a major restructuring. The ILEP strategy states the direction of the ILEP membership globally and in countries where we are working. It also shows the contribution that achieving our goal of a world free from leprosy brings to broader efforts in tackling health, disability, development and human rights.

Purpose of the strategy

- To combine forces to achieve a world free from leprosy and recognise the important role that all ILEP Members play in stopping the transmission of leprosy, preventing disability and promoting inclusion;
- Expand partnerships globally, regionally and at national level to intensify the engagement to achieve a world free from leprosy;
- Track progress and promote learning to achieve the goals the ILEP Federation has set itself and,
- Accelerate efforts and act with urgency to reduce the number of people suffering from a preventable and treatable disease.

This strategy was devised during 2015 with extensive stakeholder consultation and working with the ILEP Members. It is divided into three areas with the following aims:

1 Strategic Goals – What the ILEP Federation aims to achieve:
- Strategic Goal 1: We will work together and with other partners to stop the transmission of leprosy
- Strategic Goal 2: We will work together and with other partners to prevent disabilities from leprosy
- Strategic Goal 3: We will work together and with other partners to promote inclusion of people affected by leprosy

2 Enabling Actions – How the ILEP Federation will achieve these Strategic Goals:
- Enabling Action 1: We will improve ILEP collaboration to achieve our Strategic Goals
- Working better together to achieve our Strategic Goals
- Enabling Action 2: We will work in partnership with others to achieve our Strategic Goals
- Working better with others to achieve our Strategic Goals
- Enabling Action 3: We will raise the profile of leprosy and its consequences to achieve our Strategic Goals
- Working better together to raise the profile of leprosy

3 Operational Strategy – How the ILEP Office will facilitate this strategy:
- Operational Aim 1: ILEP Office will facilitate effective governance of the ILEP Federation.
- Operational Aim 2: ILEP Office will coordinate the Federation to monitor achievements and promote learning in the achievement of the ILEP strategy.
- Operational Aim 3: ILEP Office will lead the development of policy, advocacy and communication initiatives in collaboration with the Members.

To download a copy of ILEP’s 2016 – 2018 strategy, please visit www.ilepfederation.org/about-us/strategy
Working better together to achieve our Strategic Goals

Executive Board and Members’ Assembly

We have streamlined our Governance and elected a new Executive Board, comprising five Members, which reports to the Members’ Assembly.

The Members’ Assembly is comprised of all the heads of Member agencies. In 2015, it agreed the new ILEP constitution, new byelaws, the new strategy and budget, the formation of a new advisory panel of women and men affected by leprosy and approved the new Chief Executive Officer.

The Executive Board formulates and regularly reviews our strategic aims and ensures that our policy and practices are in keeping with our aims, vision and values. During 2015, the Board worked on the appointment of the new Chief Executive Officer, supported the development of the new strategy, provided guidance on developing the Members’ Assembly meeting and promoted ILEP externally with our key partners such as the World Health Organization, the NTD NGDO Network, the International Disability and Development Consortium, The Nippon Foundation and the Novartis Foundation.

The Board members, appointed for three years (2015 – 2017) are as follows:

Jan van Berkel, President
jv.berkel@leprastichting.nl

Bill Simmons, Vice President
bsimmons@leprosy.org

Burkhard Komm
Burkhard.Komm@dahw.de

Sarah Nancollas
SarahN@lepra.org.uk

René Stäheli
Rene.staeheli@fairmed.ch
Working better together to achieve our Strategic Goals

ILEP is guided by two Advisory Boards.

**ILEP’s Technical Commission**
ILEP’s Technical Commission, known as the ITC, is the technical advisory board of the Federation, providing advice to our Members. It is comprised of nine internationally renowned leprosy experts. During 2015, the ITC held two productive meetings with the Executive Board and agreed to extend their mandate throughout 2016 to guide the changes within ILEP.

The ITC has a wide remit. It continues progressing the participation of people affected, reviewing and providing commentary on the latest epidemiological data, providing critical guidance to the WHO and its new strategy, providing editorial in the Leprosy Review, supporting the International Leprosy Congress and, engaging with NTDs, including monitoring progress with the London Declaration.

**Panel of women and men affected by leprosy**
Of particular note this year has been the formation of an advisory Panel of women and men affected by leprosy, whose mission is to:

a) Work with ILEP’s staff and governance to understand ILEP’s work better

b) Consult with others affected by leprosy to gather their views on how ILEP can improve its collaboration with people affected by leprosy in order to improve the impact of its policy and programmatic work

c) Make a series of practical recommendations to ILEP’s Members’ Assembly in 2016 for charting a more permanent way forward of impactful collaboration.

Our thanks go to Rachna, José, Mathias and Kofi for taking on this important mandate and we look forward to seeing how we can implement their recommendations to better serve those we seek to support.
Working better together to achieve our Strategic Goals

In order to achieve our Strategic Goals and ensure we are making the most of the vast knowledge and experience within the ILEP family, 2015 saw the introduction of two new approaches to improve coordination and collaboration: development of country level strategies and thematic Working Groups.

Country level strategies
To operationalise ILEP’s new strategy, country level strategies are being developed to implement international strategy at the country level and enable us to report on collective results. India, Brazil and Nigeria are all in the process of developing country level strategies and ILEP will continue to facilitate this process during 2016.

Working Groups
At the ILEP Collaboration meeting in October 2015, ILEP launched three new Working Groups, each aligned to ILEP’s Strategic Goals: stopping transmission of leprosy, preventing disabilities from leprosy and promoting inclusion of people affected by leprosy. The three Working Groups are a core component to achieving ILEP’s Strategic Goals by:

- Facilitating knowledge transfer between organisations,
- Developing ILEP policy and advocacy messages,
- Ensuring communications have clear messages and achieve a specific and intended impact,
- Improving effective results monitoring.

Please see the Members’ Login area on the website for details about the Working Groups.

www.ilepfederation.org/members-login

International Disability and Development Consortium
Over a billion people in the world, one in seven, experience disability. While they have the same general healthcare needs as others, they are twice as likely to find the skills of healthcare providers and healthcare facilities inadequate for meeting their need. In addition, half of all people with disability cannot afford healthcare and they are 50% more likely than others to suffer catastrophic health expenditure. In such cases, out-of-pocket healthcare payments can push their families into poverty.

IDDC is a global consortium of disability and development non-governmental organisations.
ILEP, AIFO, FAIRMED, NLR and TLMI attended the IDDC’s General Assembly in May. The meeting focused on the Convention on the Rights of People with Disabilities, an interesting area for ILEP’s engagement. It also presented a chance to consider how ILEP might share the wealth of work that IDDC is involved in and what we could learn by the way IDDC members take part in their various Task Groups.

During the year ILEP has supported IDDC in various ways, including advocacy on the SDGs, pushing for the inclusion of indicators disaggregated by disability and speaking on behalf of IDDC in events in Geneva and notably during the International Day of Persons with Disabilities in December.
Working better with others to achieve our Strategic Goals - Collective Advocacy

World Leaders adopt UN Sustainable Development Goals to eradicate poverty by 2030

On 25 September 2015, 193 Heads of State met in New York to adopt 17 new universal goals and targets for tackling global development which replace the eight Millennium Development Goals which expired at the end of 2015. These new goals and targets will shape individual country policies over the next 15 years, so what does it mean for ILEP?

Thanks to the collective lobbying of the ILEP Members in conjunction with partners in the NTD and the disability communities, there are two victories for our work on leprosy in these goals: the focus on disabilities and the focus on NTDs.

LEAVE NO ONE BEHIND

The focus on disabilities
The 2030 SDGs herald a fundamental shift in promoting, protecting and fulfilling human rights for all and ILEP should be celebrating that persons with disabilities are integrated into these goals. This is particularly significant as the previous MDGs excluded persons with disabilities.

The focus on NTDs
The victory for people affected by leprosy is found in Goal 3. Good Health & Well-being and 3.3: “by 2030 end the epidemics of AIDS, tuberculosis, malaria and NTDs and combat hepatitis, water-borne diseases and other communicable diseases.” In October 2015, the second meeting of the Inter-agency and Expert Group on SDG indicators moved the indicator “the number of people requiring interventions against NTDs” to green.

Overview of the goals and targets relevant for ILEP’s work:
Beyond these areas there are many other opportunities within these goals that are relevant for the work of ILEP Members. These goals could help us advocate for the challenges that face the people we work on behalf of, including access to healthcare, preventing discrimination laws, promoting equality for women and children.
Working better with others to achieve our Strategic Goals - Collective Advocacy

More than 1.4 billion of the world’s poorest people suffer from Neglected Tropical Diseases (NTDs), including 500 million children. These diseases perpetuate poverty by causing blindness, malnutrition, anaemia, disfigurement, and disability, preventing children from attending school and parents from going to work.

The NTD NGDO Network - NNN

With more than 1.4 billion of the world’s poorest suffering NTDs, the increasing momentum of NGOs uniting in the mission to help tackle the effects was seen in the NNN meeting in September with over 200 representatives of the Non-Governmental Organisations gathering in Abu Dhabi to share lessons and show their support for the inclusion of NTDs in the UN’s Sustainable Development Goals (SDGs).

As a result of this meeting, the Abu Dhabi Declaration was produced, which was signed by ILEP Office and 10 ILEP Members. It affirms the signatories of their shared commitment to equitable and sustainable development and working closely together to combat NTDs.

The meeting provided an opportunity for a working group session on leprosy, which many ILEP Members attended, as well as other partners.

Since the meeting, ILEP has systematised its engagement with this increasingly dynamic NNN network

- Leprosy Working Group: Sarah Nancollas, Lepra, is the Chair of this group, supported by Tanya Wood, ILEP Office, as Vice Chair. We would like to express our considerable gratitude to Wim van Brakel who acted as co-Chair during 2015.
- DMDI Group: Wim van Brakel, NLR, is the ILEP representative for this group.
- WASH Group: Pete Garrett, TLMI, is the ILEP representative for this group.

We look forward to working together to make next year’s NNN meeting in Washington, 29 September to 2 October 2016, a success.
Working better with others to achieve our Strategic Goals

WHO GLP and the new Global Leprosy Strategy

"Accelerating towards a leprosy free world"

In 2015, WHO led the development of a new Global Leprosy Strategy. ILEP is a critical partner in being able to achieve the goals and targets within the Global Leprosy Strategy. ILEP participated in consultation meetings throughout the process of developing the new strategy along with the WHO Technical Advisory Group, many of whom are members of ILEP’s Technical Commission.

ILEP has worked closely with the GLP and aligned its own Strategy with the targets of the Global Leprosy Strategy:

- Zero G2D among paediatric leprosy patients.
- Reduction of new leprosy cases with G2D to less than one case per million population.
- Zero countries with legislation allowing discrimination on basis of leprosy.

ILEP is committed to working in partnership with the WHO, national programmes and other partners to achieve our common goals.
Working better together to raise the profile of leprosy

Communications in 2015

In 2015, there were a number of key communications achievements.

On World Leprosy Day 2015, we called for all laws that discriminated against people affected by leprosy and their families to be abolished. Our survey of the 63 countries where we operate revealed that about 19 countries still had laws in place that discriminate against people with leprosy. The UN Special Rapporteur on the right to health, Mr Dainius Pūras, was our spokesperson and Shri Dhondhi, from the Rajeev Gandhi Kusht Ashram in Raebareli, allowed us to talk about his experience of discrimination in support of the campaign.

New brand and new website

With the transition from London to Geneva, ILEP went through a rebranding process.

We built a new website www.ilepfederation.org which was launched at the end of July 2015. Our goal is that this website will become the website to visit for news and updates about leprosy. Since then we have added a Members’ password protected area of the website where a variety of information for Members only is posted.

In 2015 we started a new Communication Network, which is made up of representatives from each Member agency, many of whom are seasoned PR and media professionals. The Network’s collective role is to develop and deliver a results-based communication strategy in support of ILEP’s new strategy. We will also develop messaging that supports policy, advocacy and lobbying initiatives in addition to fund-raising and disease awareness.

During the year ahead we will work with the Panel of women and men affected by leprosy to develop a Policy in the use of language and photographs that sets out how we use language and photography to preserve the dignity of people affected by leprosy and their families. We are grateful to the Panel for their guidance throughout in the production of the new Policy.

Triple Jeopardy publication

In March 2015, we published Triple Jeopardy: Tackling the Discrimination Facing Girls and Women with leprosy. The report showed that girls and women affected by leprosy are triply discriminated against because of their gender, the disabilities that can result from the disease and the impact of its stigma. Studies also show that in some countries they are less likely than men to be diagnosed early.
Looking forward to 2016 / key events

World Leprosy Day 2016 is a key event in 2016. This year is the first in an online communication campaign that supports the global target in the ILEP strategy and Global Leprosy Strategy “zero disability in children affected by leprosy.”

This photo and Manjit’s profile are reproduced by the kind permission of The Leprosy Mission India Trust.

Manjit, aged nine, is the youngest of six siblings from Mau tehsil, district Bhind in Madhya Pradesh.

Manjit came to the TLM hospital with multiple disabilities affecting his hands and feet. It is almost unheard of for a nine year old to be so afflicted. He has had two reconstructive surgeries and one hand is undergoing physiotherapy. His right foot has also been operated upon. Once it is stable, he will undergo surgery for his left foot.

It is ILEP’s 50th anniversary this autumn and we plan to celebrate at the ILEP Collaboration Meeting and Members’ Assembly in Bern.

The 19th International Leprosy Congress is being held in Beijing, 18 – 21 September 2016, where there promises to be a significant amount of exciting leprosy news to report.
Budget highlights

The following budgets were approved by the Members’ Assembly on 9 October 2015. The audited financial reports will be made available.

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“Getting medication to hard to reach places.” Photo reproduced by kind permission of DFB