ILEP Annual Report 2016

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

Associazione Italiana Amici di Raoul Follereau, American Leprosy Missions, Austrian Leprosy Relief Association, Damien Foundation Belgium, Deutsche Lepra und Tuberkulosehilfe e.V., FAIRMED, FONTILLES, Fondation Raoul Follereau, Lepra, The Leprosy Mission International, Leprosy Relief Canada, the Netherlands Leprosy Relief, Sasakawa Memorial Health Foundation

In 2016 ILEP was pleased to welcome Effect:Hope and the Order de Malte as new Members
1. President’s Overview of 2016

In October 2016, the ILEP community gathered to mark 50 years of ILEP in Bern, Switzerland, the city where the organisation was founded half a century ago.

It was a great opportunity to meet many of you in person, and to reflect on our collective progress to date, as well as what remains to be done to achieve a world free from leprosy.

We have come a long way since 1966. Then, millions were affected by leprosy with hundreds of thousands severely impaired by the disease and/or excluded from their communities and even their families.

The availability of Multi-Drug Therapy in the 1970s proved a turning point in the fight against M-Leprae, and gave our ILEP predecessors hope that elimination of the disease was within reach.

Leprosy 50 years later

MDT has done its work, and still does every day. Numbers of recorded new cases are now down to around 200,000 each year.

Yet MDT did not deliver the final blow to this disabling and dehumanising disease.

We now know the shortfalls in detection and diagnosis and we must work with partners to address the huge hidden caseload of subclinical leprosy infections.

Can we complete the unfinished business of leprosy before the next 50th anniversary? I am convinced we can. Organisations working to end leprosy agree that we want a more holistic approach focusing on: how to stop transmission; how to stop the disease disabling people and children in particular; and, how to end all discrimination.

Zero Transmission

Post Exposure Prophylaxis (PEP) programmes for contacts of newly diagnosed patients have been introduced in six countries now, and look to be a key building block to preventing transmission.

The development of diagnostic tests and the start of the crucial vaccine testing phase (which could be available within 5 years) are powerful moves towards zero transmission.

Zero Disabilities

ILEP Members are promoting the empowerment of people affected by leprosy, and have developed models for self-care and integrated wound care. Adopting cross cutting approaches between leprosy organisations and the wider disability sector enables more people affected by leprosy to advocate their rightful case for adequate services and inclusion.

Zero Discrimination

Persons affected by leprosy are taking leadership roles and persuasively making the case for the recognition of their fundamental rights, and the need to ban discrimination and exclusion.

It is a great addition to ILEP to have the Panel of Persons Affected by Leprosy now advising us on our work. With their passion and experience, zero discrimination is coming closer.

These are just a few of many promising innovations and renewed commitments in which ILEP is active. Over the coming months and years, I look forward to witnessing our collective progress towards achieving zero leprosy.

Jan van Berkel
President of ILEP
2. ILEP’s CEO Update

50 years of ILEP! What a journey and 2016 saw us take many more steps together.

Coming together in October, we launched our Triple Zero Campaign, which focuses our attention on three ambitious targets:

- **Zero Transmission**: Stopping leprosy transmission
- **Zero Disabilities**: Preventing girls and boys being disabled by leprosy
- **Zero Discrimination**: Abolishing discriminatory laws and practices

But how will we achieve this? By building on our efforts to work better together with others and raising the profile of leprosy — as we did in 2016.

**Working better together**

We can only achieve our common goals and targets if we find ways to enhance the collective impact of our work. In 2016 we focused on our country level coordination work and developed strategies for Brazil, India, Nigeria and Nepal.

We also continued to invest in our Governance and Advisory Boards. In October, elections confirmed new Governing Board, Panel of People Affected and ITC. We would like to warmly welcome the new colleagues, while being extremely grateful for the work done by previous colleagues.

**Working better with others**

However, we will not achieve our Goals alone, but through better collaboration with partners working in leprosy, Neglected Tropical Diseases, Disabilities and Human Rights. In Beijing, a number of us met to develop an exciting and innovative Global Partnership on Zero Transmission. Similarly, the Neglected Tropical Disease NGO Network (NNN) and the International disability and development consortium (IDDC) continued to be important fora to engage in, to learn from and to contribute to, as we seek new ways to accelerate progress towards our goals.

**Raising the profile of leprosy**

Through the regular engagement of the ILEP Communication Network we continued to raise our profile on World Leprosy Day and to improve the coordination of messages and materials where possible. Highlights of 2016 included developing the Triple Zero campaign strategy and reaching agreement on how we respectfully portray people affected by leprosy through our new policy on the use of language and imagery.

Tanya Wood
CEO ILEP
3. Working towards our Strategic Goals: How we will achieve success?

Strategic Goal 1: Stopping the Transmission of Leprosy

Zero Transmission: We are stopping transmission of leprosy

What we measure: Number of cases in children - per million children

Our data collected from the ILEP Annual Country Survey shows that the number of cases in children in 2014 was 7.9 per million and in 2015 was 7.5 per million.

Such progress is encouraging, but the figures also underline the importance of improving the following areas:

Contact screening

The screening of contacts of people who have been newly diagnosed is a primary way the disease can be stopped.

Our survey found that contact screening was only being conducted in around 70% of districts in endemic countries and that the contacts of 62% of new cases were followed up and screened. This means that in almost 4 out of ten cases, those people who are at greatest risk of leprosy were not sought out to receive treatment.

ILEP Members are working in many countries to ensure contact screening is a key priority

Systems for prevention

When chemoprophylaxis and/or immunoprophylaxis is given to contacts of people diagnosed with leprosy, it reduces their chance of developing the disease themselves.

Our data indicates that only 10 countries have either of these treatments included in their national policies. The majority of leprosy-endemic countries have not included this preventive treatment in their national policies.

ILEP Members are supporting strategic prophylaxis research and treatment initiatives to improve this situation.

How we measure our work:

ILEP collects and analyses a range of data to help us understand the impact our work is having for individuals, families, communities and countries. This helps us determine what is working well, where fresh approaches are needed and which areas need more investment and support.

In 2016 ILEP conducted a number of initiatives to improve how we measure our work. We aligned our indicators with WHO Global Leprosy Programme indicators, worked with the Global Leprosy Programme on their Monitoring Guidelines and with Uniting to Combat NTDs on measuring progress towards the London Declaration.

We also improved our Annual Country Level survey, which gathers data from members on our strategic indicators. In 2016, we received 39 responses. Some of the key findings are in this report and the full details can be found here.

We also conduct research to find more information as needed, as we needed to do for achieving Zero Discrimination.

We still have a long way to go to improve our data collection and collective analysis, but in 2016 we saw some important strides forward to improve this aspect of our work.
Case study: prophylaxis

The Leprosy Post-Exposure-Prophylaxis (LPEP) project is a collaboration between several ILEP members and external partners. The project was launched in six countries* in 2015 and tests the feasibility and effectiveness of a single dose rifampicin as leprosy post-exposure prophylaxis.

As part of the LPEP project, asymptomatic contact persons will be offered a single dose of rifampicin, reducing the risk of developing leprosy by 50 to 60% in the following two years.

The overall aim of the project is to demonstrate that chemoprophylaxis for contact persons of newly diagnosed leprosy patients is feasible and efficient, so that it can become routine practice in all endemic countries to work towards Zero Transmission.

* Indonesia, India, Nepal, Myanmar, Sri Lanka and Tanzania

Strategic Goal 2: Preventing disability due to leprosy

Zero Disabilities: Preventing girls and boys from being disabled by leprosy

What we measure: Average number of new cases with visible impairments per million population.

Our Annual Country Survey showed that the average proportion of people developing additional impairments during or after treatment was 3.3 in 2014 and 3.2 in 2015. This equates to 5% of MDT patients in 2015.

Assessing a person’s impairments at the completion of MDT is important because ongoing and increasing impairments can affect people after completion of treatment, and cause negative physical and social consequences.
Our survey found that on average only half (53%) of people affected by leprosy are assessed for impairment and disability at completion of MDT. ILEP Members are working to improve the measurement of impairment, and the data available on residual impairments.

Case study: Poonam

When Poonam was 13, she began to notice dark patches of skin on the side of her neck and then her hand. She was developing a clawed hand and was worried: “I didn’t understand why I was getting injuries on my hand,” she said. One year after her symptoms began she received her diagnosis: leprosy. Soon after her diagnosis, Poonam started a course of MDT and received reconstructive surgery on her hand.

We want to see more active detection and early diagnosis, which are crucial if we are to achieve the WHO global target of Zero Disabilities in girls and boys. We specifically need to focus our efforts highly endemic countries and highly endemic pockets within countries.

Poonam’s journey could’ve been very different, had the disease not been detected and the impairments treated. Instead, her story demonstrates the importance of intervention and treatment to people’s quality of life. Poonam is now married to a supportive husband. No visible signs of her leprosy remain, and she is happy and optimistic about the future.
Strategic Goal 3 Promoting Inclusion of People Affected by Leprosy

Zero Discrimination: Abolishing discriminatory laws and practices

What we measure: Number of laws in place that discriminate against people affected by leprosy – Our results in 2015 show that there are currently 50 in place.

As well as our Annual Country Survey, during 2016 we conducted two critical pieces of work to inform the work required to achieve Zero Discrimination.

Laws and official practices that discriminate, segregate and isolate people affected by leprosy from their communities, and even their families, must be abolished. Our research during 2016 showed that there are still many of these in place globally. Information on the laws and where, can be found here.

ILEP Members are working to identify and abolish these discriminatory laws and promote positively inclusive laws and regulations (which are now in place in fourteen countries).

ILEP recognizes that it is vital to have people affected by leprosy and their associations engaged in services, as resources for advocacy, prevention, health education and detection. Our survey found that in 44% of countries, the opportunity of actively involving them in these roles was missed.

These findings were backed up by a substantial survey spearheaded by the Chair of our Panel of People Affected by Leprosy, Mathias Duck, who looked at the connection between policy and practice. His findings showed that despite action to reduce discrimination, respondents to a survey continued to face discrimination at home, at work, in their personal relationships, and in their access to public spaces. More information can be found here.

Key findings from Mathias Duck’s “Making a difference to Policy and Practice” presentation
4. How are we working together and with others?

4. A. Working Better Together

ILEP’s Global Projects Map: Insights into Who, What and Where?

During 2016, ILEP Members contributed to the production of a digital, interactive map showing where and what they are working on.

Where: The result is an impressive visual overview of the work being done in 519 different projects in more than 61 countries worldwide.

What: Analysis of the information provided shows that ILEP Members support and provide a broad range of activities. Ten categories were identified and the projects were found to be fairly evenly split addressing each of the three “Zeros” (See below: Zero Transmission activities – Green, Zero Disabilities activities – Blue, Zero Discrimination activities – Red)

How? Analysis of these data also reviewed how ILEP Members achieve their work. The majority of their outcomes are through collaborations. The majority (about 80%) of the work undertaken by ILEP Members supports existing facilities, local agencies, national programmes, local NGOs, hospitals and clinics, etc.

The analysis also demonstrated that the primary way ILEP Members work is through building capacity. This is done at multiple levels, from the person and community level (“downstream”), to improving the delivery of local services in various ways (“midstream”), and to providing higher level technical and strategic support (“upstream”).
Reviewing how we are working together: A Membership review

During 2016 we undertook a survey open to all staff working in the ILEP Membership to look at ways of improving how we work together. Operational aspects of communications, ILEP at country level and governance and advisory functions were examined. The feedback demonstrated that Members believe communications are very important and should aid coordination between members, with an emphasis the sharing of information and resources.

It also showed there is considerable support for greater ILEP engagement at country level and linking these agencies with international agendas. Furthermore, members believe there is potential for greater involvement of people affected by leprosy at every level.

ILEP Members can read the full analysis of the Membership Review here.

Improving how we work together at Country Level

Working together at country level is of critical importance to ensure we are maximising our work where it matters most. To do this effectively ILEP members committed to producing

Country Level Strategies. In 2016 we are pleased to report we produced four country strategies in India, Brazil, Nepal and Nigeria. At the ILEP October Meeting, the Country Representatives came together to continue their commitment to this process.
4. B. Working Better With Others

If we are going to achieve a world free from leprosy, we cannot do this alone, but by working with others to find more effective means to reach our Goals.

Deepening our Partnership with others working on leprosy: towards a Global Leprosy Partnership on Zero Transmission

Through a desire for increasing our collective efforts in achieving a world free from leprosy, a number of partners came together to meet in Beijing in September 2016 to consider the potential for developing a new Global partnership on leprosy. The meeting, jointly hosted by ILEP and Novartis Foundation, confirmed a commitment to establish a partnership across leprosy stakeholder groups, which will launch in 2017.

Deepening working with others on Neglected Tropical Diseases

Leprosy is not an isolated disease. If we are going to fight this disease, we have a lot to learn from collaboration with others working on other Neglected Tropical Diseases (NTDs). During 2016 we continued to deepen our relationship with the NGO Network for Neglected Tropical Diseases, taking a leadership role on helping them develop a new Framework for Engagement to strengthen the network.

At the NNN meeting in 2016, Sarah Nancollas of Lepra and Tanya Wood of ILEP were elected as Vice Chairs to this network.

Deepening our work with the Human Rights Community

In August 2016, the long-awaited preliminary report on the implementation of the Principles and Guidelines behind the UN Resolution on the “Elimination of discrimination against persons affected by leprosy and their family members” was presented. ILEP’s questionnaire informed the preliminary report, which set out four initial recommendations:
1. **Awareness campaigns** regarding the Principles and Guidelines
2. **Identification of discriminatory national policies, laws and practices** against people affected by leprosy and their family members and amend or repeal such discriminatory laws.
3. **Participation and involvement of people affected by leprosy**
4. **A dedicated mechanism within the existing United Nations Human Rights machinery** to follow-up, monitor and report on progress

We welcome these recommendations, particularly the inclusion of people affected by leprosy in the decision-making process, the reference to achieving zero discriminatory laws, and the focus on women, girls and vulnerable groups. ILEP will continue to highlight how the participation of persons affected by leprosy currently falls short of the standard, and to call for States to do more to actively identify discriminatory laws and for these laws to be abolished.

### 4. C. Raising the Profile of Leprosy

Leprosy is recognized as one of the world’s neglected tropical diseases, but we are committed to ensuring that the disease and the people affected by it are not forgotten.

In early 2016, the ILEP Communication Network was formed to help keep leprosy on the international agenda, through international initiatives such as World Leprosy Day and the coordination of messages and materials where possible.

Raising the profile of leprosy and its consequences is a central part of the Triple Zero campaign strategy, launched in October 2016 in Bern. Stopping leprosy transmission (Zero Transmission), preventing girls and boys being disabled by leprosy (Zero Disabilities) and abolishing discriminatory laws and practices (Zero Discrimination) require effective communication with target audiences to achieve results. This can take many forms including persuasive advocacy to change legislation, encouraging knowledge sharing and evidence tracking, or developing innovative partnerships with agencies in different fields such as children’s welfare or human rights.

The new-look ILEP website was launched in Bern to support and reflect the new campaign. See [www.triplezerocampaign.org](http://www.triplezerocampaign.org)
5. Budget Highlights

The following shows income and expenditure details for 2016. The audited financial reports are available upon request.

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<tr>
<td>Membership Contributions</td>
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<td>Additional approved Income</td>
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<table>
<thead>
<tr>
<th>Expenditure</th>
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<td><strong>Total Expenditure</strong></td>
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