ILEP ANNUAL REPORT 2019

Working together to stop leprosy, prevent disability and break the stigma resulting from leprosy
YEAR IN NUMBERS – at a glance

- ILEP Members: 13
- Countries we work in: 69
- Projects in 740 locations: 346
- New cases reported (WHO): 208,619
- New cases with visible disabilities (WHO): 11,323
- New child cases (WHO): 16,013
- New female cases (WHO): 83,128
- Persons living with visible disabilities (WHO): 3-4 million
- People at risk of leprosy (WHO): 30 million
- Discriminatory laws worldwide: 132
Working together to stop leprosy, prevent disability and break the stigma resulting from leprosy.

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The goal of a world free from leprosy puts us as NGOs in a pivotal position. We initiate and coordinate the multi-stakeholder involvement that is necessary for effective national partnerships, which will lead to the roadmaps towards zero leprosy: zero transmission of the disease, zero disability and zero discrimination. Uniting all leprosy stakeholders towards one ambitious agenda and roadmap will make our joint efforts better aligned and more effective.

As expected, this year we began to see potential partners and funders show growing interest in the Global Partnership for Zero Leprosy (GPZL) and its business case for zero leprosy. GPZL is now moving into its operational phase where one of the main tasks is to work towards achievable leprosy goals at country level, focusing on an additional five countries in 2020.

Our efforts to contribute to effective approaches to cross-cutting issues like zero disability and zero exclusion are gaining momentum in other neglected tropical disease (NTD) communities.

There is increasing interest in the work ILEP Members do to further the empowerment of persons affected by the disease and to facilitate and support their active involvement in all aspects of our strategy. Our active involvement in the NTD networks has also been helpful in bringing the needs of the leprosy world to the attention of the wider NTD community. Major NTD donors have started including leprosy in their calls for proposals.

We keep on exploring opportunities to promote integration on cross-cutting issues between leprosy, Skin NTDs and other disabling diseases. We are all paying increasing attention to the needs and health seeking patterns among populations at risk and persons affected. These perspectives will drive ILEP Members forward in the coming years of this Partnership Era, envisioning a day when zero leprosy transmission, zero disability and zero exclusion are a reality.
MESSAGE FROM THE CEO

Geoff Warne, ILEP CEO

“ILEP Members continue to strive to be a model for neglected tropical disease (NTD) partners by promoting the participation of persons affected by leprosy.”

An important global advance in 2019 has been the World Health Organization’s (WHO) development of a ten-year Neglected Tropical Diseases (NTDs) Roadmap. ILEP worked with WHO on the leprosy targets and strategy for the Roadmap. With other NTD partners we successfully lobbied to include actions that respond to the long-term health issues, disability and social exclusion that blight the lives of people affected by leprosy and many other NTDs. We anticipate that ILEP Members will increasingly work with other NTD organisations at country level. We continue to strive to be a model for NTD partners in promoting the participation of persons affected by leprosy.

We grasped opportunities in 2019 to engage with the UN human rights bodies. We held leprosy awareness sessions with the committee that oversees the Convention for the Rights of Persons with Disabilities (CRPD), made detailed submissions on the leprosy situation in countries being reviewed by UN human rights bodies, and co-organised an event during the Human Rights Council featuring UN Special Rapporteur Alice Cruz and eloquent speakers with personal experience of leprosy.

ILEP Members continued to be very active in the Global Partnership for Zero Leprosy (GPZL). A ‘country model’ was launched mid-2019, incorporating review of the national leprosy programme, a jointly developed roadmap towards zero leprosy, and a toolkit of best practice along with a helpdesk. As GPZL starts to roll out this model in 2020, ILEP Members will be actively involved in all aspects: review, planning and implementation. Our commitment is to a world free from leprosy, and we strive with our partners towards the ‘three zeroes’ that will make that real: zero transmission of leprosy, zero disability and zero stigma and discrimination.

GIT
Our vision is a world free from leprosy
How things are

A major challenge for the leprosy world is that the number of new cases of leprosy per year has hardly changed over the past decade.

In the next five years, more than a million people will catch the disease, with all its multitude of consequences for the individual, family and community. To start a real downward trend in leprosy transmission, we need new tools along with a determined, widespread implementation of best practice.

The stigma associated with leprosy remains one of the chronic barriers to ending transmission. People fear being labelled with leprosy and are therefore reluctant to get diagnosed or seek help. Lack of awareness of the symptoms is another barrier. Individuals may seek help only when disability sets in, and health services may not recognise the disease or know how to manage it.

Even where awareness raising, early diagnosis and leprosy treatment programmes are implemented well, they are not producing the hoped-for reduction in new cases. Transmission may be occurring before treatment has started, so early detection is essential.

The absence of a diagnostic test to detect early leprosy before it becomes clinically apparent, and the absence of a vaccine, are both severe limitations in leprosy diagnosis and prevention.

Active measures to identify leprosy early include examining the close contacts of new cases. Anyone with signs of leprosy can be immediately started on treatment. Offering post-exposure prophylaxis to contacts has been found to have a protective effect, but hurdles need to be overcome for its scaling-up into all disease-endemic areas.

How we are working for positive change

One of ILEP’s primary roles, working alongside national leprosy programmes, is as a source of expertise. This expertise was mobilised in the provision of best practice examples for the Toolkit developed by the Global Partnership for Zero Leprosy. During 2019 ILEP personnel were a strong presence at the triennial International Leprosy Congress, at the annual NGO Neglected Tropical Diseases Network (NNN) conference, in comprehensive reviews of the status of the leprosy programmes in India and Nepal, and at the most high-level national leprosy conference in decades in Bangladesh. Each of these was the first step towards detailed zero leprosy roadmaps in which ILEP Members will be key partners.
At country level, ILEP Members work closely with governments and other partners to advise on and model active case-finding and contact-tracing programmes. They work with government staff to build capacity and advocate for governments to invest in these programmes. Several ILEP Members supplement the work of governments by running case detection activities, especially in hard to reach areas. Some of these activities bring to light surprising numbers of new cases of leprosy. Early detection and prompt treatment remain the cornerstones of well-run leprosy programmes.

ILEP Members were active in the WHO Skin NTDs conference in March, as well as in several other WHO-hosted events, some leprosy-specific and some including other NTDs. GPZL and ILEP Members gathered in November to review the ‘state of the art’ in post-exposure prophylaxis (PEP), a potential game-changer in leprosy prevention, and to work on a guide for implementation in the field. One workstream sought to define the continuing research issues and plan how they can be addressed.

Seven ILEP Members were involved in large-scale research projects spanning more than thirteen countries. This research aims to demonstrate the most effective and feasible approaches to PEP implementation and identify more potent PEP regimens.

Meanwhile LepVax, a potential leprosy vaccine, has completed clinical safety trials in the US and will now proceed for a second phase of clinical trials in 2020-2021 among communities at risk of leprosy. The trial will run for two years. Aside from these initiatives, most ILEP Members invested in research during 2019, whether in the form of dedicated research facilities, specific long-term research projects, operational research, or through the pooled research budgets that enabled the Leprosy Research Initiative to invest around €1.4 million in research during 2019.
Amar was diagnosed with leprosy during his early years and was rejected by his community as a result. From 1989 to 1995 Amar was successfully treated. His experience inspired a fierce desire to advocate for the rehabilitation of people affected by leprosy in their families and communities.

“For me, leprosy came as a boulder that stopped me on my path. I had to struggle so much that my energy and my will was almost gone. My initial perception of the disease was not so different from what society understood it to be. Later on, my perception changed when I was completely cured. With the help of education and financial freedom I was able to change the perception of the community, of society, and that helped me to stand in this position now.

There is no reason why the people affected by leprosy need to be undervalued or taken as someone who is less. For me leprosy is a disease as common as headache and toothache in the sense that it is completely curable.

But I was compelled to leave my birthplace, to leave my school, even to sign divorce papers due to the extreme stigma of this disease.

Even today, medical professionals do not understand leprosy and our situation well enough. They don’t understand the real pain and suffering of the people affected by leprosy. Many health professionals are retiring from their jobs. We have to give trainings to the young generation so that they can develop the expertise themselves.

Over the last decade, the dignity of people affected by leprosy has been raised. Now, we have organisations of people affected by leprosy and we can raise our own voice: we go to many doctors, hospitals, visit government people and they listen to us. For example, there is a discriminatory law in Nepal. If I say I am a person affected by leprosy, my wife can give me divorce. The organisation of people affected by leprosy, IDEA Nepal, is working very hard to raise our issues to abolish this law.

What I feel, after the treatment is applied to the people affected by leprosy, the next biggest challenge today is the discrimination and their reintegration into society. So, the financial freedom for the people affected by leprosy must be provided so they can have the dignified life.”

**Shortened for publication**
Our mission is to work together to stop leprosy, to prevent disability and break the stigma resulting from leprosy.
Disability support and rehabilitation needs are far greater than ILEP alone can meet. ILEP Members advocate that the disability services and supports that leprosy affected people need should be provided by their governments.

How things are

Leprosy has resulted in damaging impairments for up to 6 million people alive today. The disease attacks the nerves, so that some people cannot feel cuts and burns and become more prone to wounds which can lead to disability.

Untreated leprosy can also cause muscle weakness which may lead to damaging consequences for a person’s hands, feet and eyes. Moreover, many patients experience inflammatory reactions to the leprosy bacteria still present in their body, resulting in sometimes very severe pain along with sickness and swelling. Reactions are notoriously difficult to treat, and repeated reactions are immensely discouraging for the individual.

Although clinicians can test for nerve function impairment and for loss of sensation, in most countries this is sporadic. Skills in recognising reactions, and knowing how to treat them, are also lacking: people with leprosy reactions may not be properly assessed or treated.

Even when the right treatment pathways are known, reaction management often involves very prolonged treatment with steroids, with serious potential health consequences especially in low-resource settings.

Leprosy-related impairments represent a very high cost to individuals, families and communities. The activity limitations that result from damage to hands, feet and eyes can rob people of their livelihoods and cause difficulties in the normal daily activities of life. Because most government programmes assess disability only at the point of diagnosis, there are no statistics for the real situation of disability, nor for the worsening of impairments over time.

How we are working for positive change

During 2019, several ILEP Members offered or supported the provision of reconstructive surgery, ulcer care and assistive devices that can help people overcome the limitations caused by leprosy impairment. Surgery, along with physiotherapy, can restore function to hands and feet and enable eyes to blink again.
ILEP Members supported government programmes in supplying footwear that helps a person with no feeling in the feet to avoid damage when walking.

But there is a wide gap between the number of people who need surgery, or footwear, and what is actually provided. So ILEP Members lobby for governments to step up and provide these services as standard.

ILEP Members also helped to teach daily self-care exercises to people who lack feeling in their hands or feet. The purpose is to avoid worsening physical damage. In some countries this is done at the community level through the formation of self-care groups that contain people suffering not only from leprosy but also from other conditions needing self-care.

Through community-based rehabilitation ILEP Members have focused on enabling people to develop new livelihoods if the risk of physical damage means that their previous work cannot continue, and on fostering social inclusion. Here too, the needs are far greater than ILEP alone can meet, so ILEP Members have advocated for access by leprosy affected people to the disability services and supports that they need and which governments should provide.

At the international level, ILEP engaged actively in 2019 with the Committee that oversees the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD Committee has recognised that leprosy falls under its mandate. There were opportunities during the year for a lunch meeting with the Committee focused solely on leprosy, to address the Committee at each of its opening sessions, and to make written and verbal submissions relating to countries where there are human rights issues for people affected by leprosy and disability.

During the year, ILEP also worked, partly in association with the Neglected Tropical Diseases Network (NNN), to advocate with the World Health Organization around the newly developing NTD Roadmap. We have sought to ensure that the cross-cutting sections of the Roadmap provide for essential care packages for those diseases like leprosy that have ongoing consequences in terms of disease management, disability and social inclusion.
Rachna’s goal in life is to help other people with leprosy. She does this every day with rare patience and compassion, teaching people how to care for themselves.

She is also a key member of the State Forum of leprosy affected people in Bihar, through which she helps raise awareness in leprosy colonies and advocates for their rights to a life of dignity.

“In our community leprosy is the untouchable disease. People are thinking, you suffered from leprosy, that means that in your past life you did not do good work, then you receive this disease. Please go outside, don’t play with her, don’t eat with her, and don’t do anything like cooking, reading, anything with her because she suffered from leprosy. I am not touching her. People are not aware leprosy is curable, that you can go there and take the medicine, free of cost.”

In our community, some doctors are untrained in leprosy. Other doctors know about leprosy and early detection, so they know what problems these people are facing. But even knowing about everything, the doctor does not touch you. See he’s scared.

Awareness is really important. Every man and woman who reaches the government hospital and private health clinic needs to know about leprosy in India. So, we can put some positive images on the wall: she is diagnosed early, she is much happier, now she is cured. Everyone can look at the picture and see the point. Minds are changed. But in our community people are not aware, not educated, so the problem is very big.

At Lepra India, my work is community mobiliser. Sometimes I go to the field, to the development officer or the Welfare Society or the hospital. Sometimes people are coming to my Lepra centre. I am counselling, I talk about the self-care and diagnosis. I had suffered from stigma and discrimination, economical problem, mental problem, depression – I don’t want anyone to suffer this. I’m happy with my work, because those people are happier. I see their face. I’m so happy because I change someone’s life.

Now I am the example for all women in my struggle with the disease and the economic condition. Then I achieved this platform and I am here, not only me, but on behalf of all women, all women’s voice.

**CASE STUDY: Rachna Kumari**

Rachna’s life purpose is to help other people with leprosy. She does this every day with rare patience and compassion teaching people how to care for themselves and how to advocate for their rights.

**Shortened for publication**
ILEP aims to keep leprosy stigma and discrimination on the agenda of all UN human rights bodies, while supporting advocacy by ILEP Members in-country to bring these abuses to an end.

How things are

Negative, sometimes hateful, community attitudes can be the most troubling and the most disabling consequences of leprosy. There is no medical justification for this prejudice: it is a social invention, a label.

The constant exclusions that people affected by leprosy face in the daily business of living result in poverty, dehumanisation, mental torture, despair, even suicide. This is the daily reality for up to 5 million women, men and children today. In addition to this discrimination at community level, more than 20 countries keep discriminatory laws in force against persons affected by leprosy. India alone has around 100 such laws, and it is a challenge to get these laws amended or repealed.

In theory there are protections. In 2010 the United Nations adopted Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members. These Guidelines form an excellent guide for governments on how to assure the human rights of persons affected by leprosy.

But they are not mandatory and have largely been ignored, and so the same segregating patterns persist.

Some studies have been done into the causes of stigma, but knowledge, beliefs, fears, attitudes and practices are by no means uniform across countries and communities. This means that more research, and the validation across cultures of existing research, are needed if our interventions to end stigma and support mental wellbeing are to be effective.

How we are working for positive change

During 2019 ILEP continued to take the lead in cataloguing discriminatory laws. At year-end, 132 laws remained in place, down from 155 a year earlier. ILEP has been at the forefront of pushing for change, both through advocacy in-country and through oral and written submissions to the relevant UN human rights mechanisms.

Several ILEP Members worked together during 2019 to complete the rewriting of ILEP’s Stigma and Mental Wellbeing Guides.
These Guides apply to a range of stigmatising health conditions, including leprosy. There are plans, in association with the NGO Neglected Tropical Diseases Network (NNN), to ensure that they are taken up by as many countries as possible.

It is important for ILEP’s decisions to be influenced by the voice of persons affected by leprosy. The ILEP Advisory Panel, which meets twice a year, consists of five women and men with personal experience of leprosy, each of them with active links into communities of leprosy-affected people in their own countries. During 2019 the Panel worked on a policy for participation by persons affected by leprosy in the decisions being taken by ILEP Member associations. This is a challenging topic which will be brought to conclusion in 2020.

Leprosy-affected people’s organisations are making a major contribution to challenging stigmatising attitudes and defending the rights of people affected by leprosy. ILEP Members have taken initiatives over many years to support the establishment of these organisations.

In 2019 ILEP member Sasakawa Health Foundation organised the first Global Forum of People’s Organizations on Hansen’s Disease (leprosy) in which 60 persons from 23 countries shared experiences and aspirations. The ILEP Advisory Panel had a strong voice in this Forum.

The Global Forum has given further impetus towards ensuring that people affected by leprosy have a more inclusive role in the global campaign against leprosy.

In 2019, ILEP co-organised a leprosy-focused event during the Human Rights Council, with high-profile speakers from UN bodies, including the UN Special Rapporteur for Leprosy, and speakers from India and Brazil with personal experience of leprosy.

In addition, ILEP made oral and written submissions to the UN human rights bodies, aiming aim to keep leprosy stigma and discrimination on the radar of the UN and to complement advocacy by ILEP members in-country to bring human rights abuses to an end.
Paula discovered she had Hansen’s disease during her last term in nursing at University in 2002. In 2009, she began her master’s degree, and continued to research Hansen’s disease for several years. In 2015, Paula began a teaching career at the Nursing University of Rio de Janeiro, where she ensures that all her students are well-educated on Hansen’s disease.

“I never say leprosy because in Brazil we say Hansen’s disease. When I got my diagnosis, the first thing in my mind was ‘I have leprosy’, and that means bad things will happen. My family, friends, work will segregate me. Then I understood I didn’t have leprosy, I had Hansen’s disease. Leprosy is a Biblical word and a historical, stigmatised disease. Hansen’s disease is the current disease, the curable one. I was one Paula before the disease and another Paula after the disease. Initially I became very depressed and shy. Treatment caused a change in my skin colour and everybody said, wow, Paula you have beautiful skin.

I told them I was going to the tanning machine. I became fat with the medication, and that wasn’t good because in Brazil the woman needs to be a beautiful woman, I feel. I now know other people with Hansen’s disease. I can help other people who suffer from stigma or have self-stigma. I have the conditions to change the situation because I have a good family, friends and profession and I get support from them.

Stigma is a situation society creates. The worst part is the segregation. It’s not possible one person lives alone in life. You need other people, to love, to care. I’m very sad when I see people segregating other people. But we can change this.

We are the people affected by Hansen’s disease but also, we are the citizens, we have a life, our friends, our family, marriage or a boyfriend/girlfriend, we are human.

We bring our voice to show the medical profession and all the society that what we need is respect of our rights, the right of the voice, of social participation. I think women and children suffer more than other persons, but everybody needs to have the same rights. I feel a better world, a better country, a better community and we fight to improve this.”

Paula feels that people affected by Hansen’s disease now have a voice. But they need to continue to show society and medical professionals that their rights must be respected. She will continue to talk about the problems she has faced, her decisions, and the rights that everyone affected by leprosy deserve.
ILEP continues to focus on the stigma surrounding leprosy
FINANCIAL HIGHLIGHTS 2019

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

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<th>Financial Highlights</th>
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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.

American Leprosy Missions
Associazione Italiana Amici di Raoul Follereau
DAHW (German Leprosy and Tuberculosis Relief Association)
Damien Foundation Belgium
effect:hope
FAIRMED
Fondation Raoul Follereau
Fontilles
Lepra
Leprosy Relief Canada
Netherlands Leprosy Relief
Sasakawa Health Foundation
The Leprosy Mission International

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