



YEAR IN NUMBERS – at a glance



13

ILEP Members



69

Countries
we work in



387

Projects in
710 locations



210,671

New cases
reported (WHO)



12,189

New cases with
grade-2 disabilities (WHO)



16,979

New child cases
(WHO)



238

New child cases
with grade-2
disabilities (WHO)



82,922

New female
cases (WHO)



29

Countries with
laws discriminating
against people affected
by leprosy



145

Discriminatory
laws
worldwide

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

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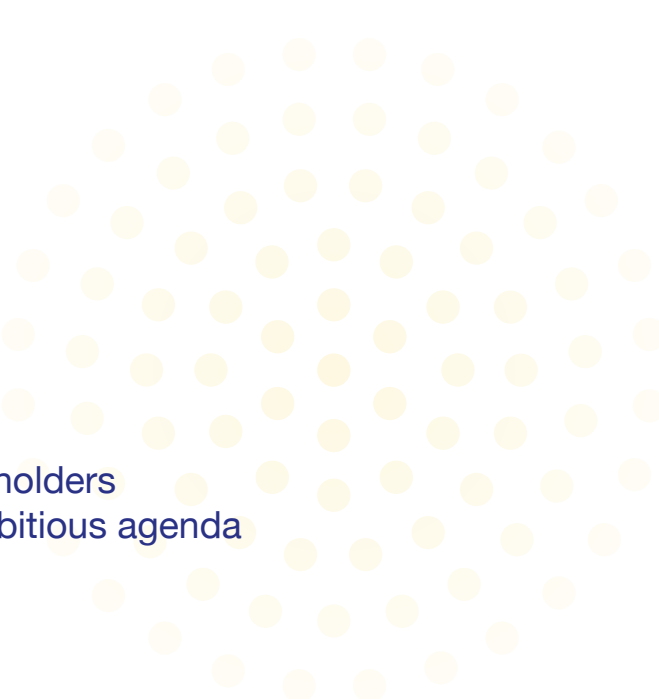


PRESIDENT'S REPORT

Jan van Berkel, ILEP President



Uniting all stakeholders
towards one ambitious agenda



“Uniting all leprosy stakeholders towards one ambitious agenda and roadmap will make our joint efforts better aligned and more effective.”

For the leprosy world 2018 was a year of changes and new perspectives. And so it was for ILEP. Tanya Wood, ILEP's first Geneva-based CEO, moved on to new challenges and we welcomed Geoff Warne as new CEO, assisting ILEP with his longtime experience in NGO federation management.

In 2018, ILEP and its Members invested resources, as well as the high involvement of their staff, in the new Global Partnership for Zero Leprosy, formally launched on World Leprosy Day 2018.

ILEP plays a key role in the Partnership at all levels: the Leadership Team, the Zero Leprosy Research Agenda and the Working Group for Operational Excellence, which translates global ambitions into national partnerships for zero leprosy.

These will unite all stakeholders and resources at country level towards national roadmaps to zero leprosy, benefiting from best practices and innovations.

Uniting all leprosy stakeholders towards one ambitious agenda and roadmap will make our joint efforts better aligned and more effective. I am sure we will begin to see in 2019 that potential partners and funders will show growing interest in the Global Partnership and its business case for zero leprosy.

A united leprosy world will raise more political will and resources at national and international levels, enabling us to bring the fight for zero leprosy to the next level of scale, quality and impact.

A handwritten signature in black ink, likely belonging to Jan van Berkel, the President of ILEP.

MESSAGE FROM THE CEO

Geoff Warne, ILEP CEO



A new momentum and sense of partnership in the leprosy world excites and motivates us

“Zero leprosy may be many years away but we believe it is possible.”

After a two-year absence from the leprosy world, I find very striking the rapid development of the Global Partnership for Zero Leprosy, whose purpose is to align the leprosy community and accelerate effective collaborative action toward the goal of zero leprosy.

ILEP, one of the founders and a core financial partner, has been a driving force for achievement within this new partnership which brings together most of the main stakeholders in leprosy today.

In only a year, we see a consolidated research agenda for leprosy almost complete, progress on an operational excellence toolkit, and design of a review process for countries serious about getting to zero leprosy. These developments involve more than 300 scientists or practitioners, many of them connected to ILEP's Member associations worldwide.

In Geneva, there are emerging opportunities to profile leprosy within the United Nations, particularly around the challenges of stigma and discrimination. Whether it's in connection with women, or children, or persons with disabilities, the UN human rights bodies centred in Geneva are showing an interest in hearing about leprosy. They are asking countries to repeal discriminatory laws and do better in preventing social exclusion in communities.

Zero leprosy may be many years away but we believe it is possible with a strong ILEP, maintaining high standards of leprosy programmes worldwide, and working closely with our like-minded partners.

A handwritten signature in blue ink, appearing to be 'G. Warne', with a checkmark at the end.



**Our vision is a world
free from leprosy**





ZERO
TRANSMISSION:

Stopping the
transmission
of leprosy

The challenge for the leprosy world is that the number of new cases has hardly changed over the past ten years. We need new knowledge and new strategies to break this static pattern and start a real downward trend in leprosy transmission.

1

STRATEGIC GOAL:

**Stopping the Transmission of Leprosy
– Towards Zero Transmission**

How things are

One of the frustrating aspects of leprosy treatment is that, although the standard multi-drug therapy is very effective at treating the disease, it is not producing the hoped for reduction in new cases.

The World Health Organization's (WHO) annual statistics on leprosy are published each year in September. Their most recent data – from a record 150 countries – tells us that there were 210,671 new cases in 2017, 80% of them in India, Brazil and Indonesia. That total included 16,979 children, which is a significant indicator that there is ongoing and recent transmission of leprosy in communities. It also included 12,179 people who were already showing signs of permanent damage caused by leprosy to their hands, feet or eyes – an indicator that people are not getting treatment early enough.

The challenge for the leprosy world is that these rates have hardly changed over the past ten years. We need new knowledge and the relentless implementation of best practice, to break this static pattern and start a real downward trend in leprosy transmission.

How we are working for positive change

ILEP's World Leprosy Day campaign in 2018 focused on the fact that, every day, 50 children are diagnosed with leprosy. It called on governments to invest in active case detection programmes in leprosy endemic areas to ensure that children are diagnosed and treated early to avoid the risk of disability. ILEP also called for strengthening targeted efforts to reach children, with special action in highly endemic countries and leprosy 'hot-spots' within countries.

ILEP scientists and researchers were intensively involved during 2018 working towards a globally agreed Research Agenda for Zero Leprosy.

Trying to prevent transmission is a focus of the Research Agenda. Three of the research subgroups were directly focused on new knowledge leading to zero transmission: a vaccine, a diagnostic test, and treatments to prevent leprosy among close contacts of newly diagnosed patients.





ZERO TRANSMISSION:

Stopping the
transmission
of leprosy

ILEP is already working on two of these.

1. The first is LepVax, a possible vaccine developed by IDRI with financial support from American Leprosy Missions and others. Phase 1 human trials were completed in 2018 and more trials will follow in 2019.
2. The other development is post-exposure prophylaxis, a preventive drug treatment for contacts of people who have been newly diagnosed. This approach is recommended in the WHO's new leprosy guidelines, published in 2018. ILEP Members have long known the advantages of tracing and examining contacts, such as family members, to detect possible leprosy: we screen or examine more than 2.5 million people a year. Now, the opportunity to provide contacts with preventive medicine adds impetus to what is already good practice. Seven ILEP Members are involved in five ongoing, large-scale research projects in more than thirteen countries, all aiming to demonstrate the most effective and feasible approaches to what could begin to break the chain of leprosy transmission.

Research on its own cannot solve the problem: it needs to be accompanied by implementation of the good practices we already know and of new, validated findings.

ILEP Members are active in health services in more than 60 countries, working closely with governments to advise on, model and co-implement active case-finding and contact-tracing programmes covering a total population of more than a billion people. In addition, during 2018, ILEP facilitated the coordination of the Operational Excellence Working Group of the Global Partnership for Zero Leprosy. ILEP Members are heavily involved in its work – both on the toolkit of best practices and on a method to enable countries to review their current status and design credible strategies to get to zero leprosy. The ILEP Technical Commission is an expert advisor to this working group.

With these initiatives, ILEP Members are strategically placed to support countries and communities to move towards the agreed zero transmission targets.





ZERO
TRANSMISSION:

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1

CASE STUDY:

Diagnosis gives answers and hope

At 12 years of age, Binta Alhassan Abubakar began to show signs of being affected by leprosy.

“Nobody knew what the symptoms were,” she said. “My father dismissed it as a common illness which would pass soon. After two years, the symptoms worsened and I was taken to a native medicine man who kept giving me herbal medications to take.”

The illness continued to progress for several years and Binta began to have problems with ulcers that would not heal.

“My legs and hands began to grow worse. That was when my father took me to Chanchaga Hospital in Minna, Nigeria. Although I started receiving treatment almost immediately, the ulcers had worsened from my legs up to my knees and from my hands up to my wrists.”


Though her recovery was long, afterwards Binta travelled back to her hometown where she married her husband of 18 years.

In 2017, Binta received startup funds to begin a sheep rearing business. The family was able to buy three sheep (two females and one male). They have now raised seven sheep and sold one. With the funds from this sale they were able to pay school fees for their children, buy them books and clothing and they have been eating well.

“What brings us great joy is that the sheep was bought by a rich non-leprosy-affected man. We were glad because our sheep was accepted by others even though they knew we had leprosy,” said Binta.

Binta Alhassan (above) and six of her family's sheep (below).

© The Leprosy Mission Nigeria



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



ZERO DISABILITIES:

Preventing girls and boys from being disabled by leprosy

Global-level advocacy complements the essential work ILEP Members are doing at country and community level to prevent disability and to promote the right of persons with disabilities to rehabilitation and other services, to social inclusion and equality of opportunity.

2

STRATEGIC GOAL: Towards Zero Disability

How things are

According to the data from 2017 collected by the WHO, 12,179 people were already showing signs of disability caused by leprosy to their hands, feet or eyes at the time of diagnosis. But this is only a fraction of the story.

A far larger number of people develop nerve damage – not so readily visible – before or during treatment. For these people, the normal activities of life – walking, running, working with their hands – result in steadily increasing damage particularly to hands and feet. As a result, an estimated 2 to 3 million people are suffering from permanent impairments due to leprosy.

These impairments and disabilities represent a very high cost to individuals, families and communities.

This is not just due to the activity limitations that result from damage to hands, feet and eyes, but also to the stigmatisation that people with visible, leprosy-related damage experience in so many communities.

How we are working for positive change

Wound care, self-care and the proper treatment of leprosy reactions are effective tools for preventing serious disability. In most countries where ILEP is active in disability programmes, people affected by leprosy have access to those services, and ILEP is having a powerful effect in reducing disability. But in half the countries surveyed, these services are minimal, and most countries do not have widespread capability in nerve function assessment.

ILEP Members need to work actively with governments to promote adoption of these basic requirements.

During 2018, several ILEP Members offered or supported the provision of life changing reconstructive surgery and assistive devices that can help people overcome the limitations caused by leprosy impairment. In some countries, ILEP Members actively promoted community-based rehabilitation, a whole-of-life approach that focuses on the adjustments people can make in order to function well, on equalising opportunities, and on fostering social inclusion. But these programmes are not available everywhere. The needs are far greater than what ILEP can currently meet.



ZERO DISABILITIES:

Preventing girls and
boys from being
disabled by leprosy

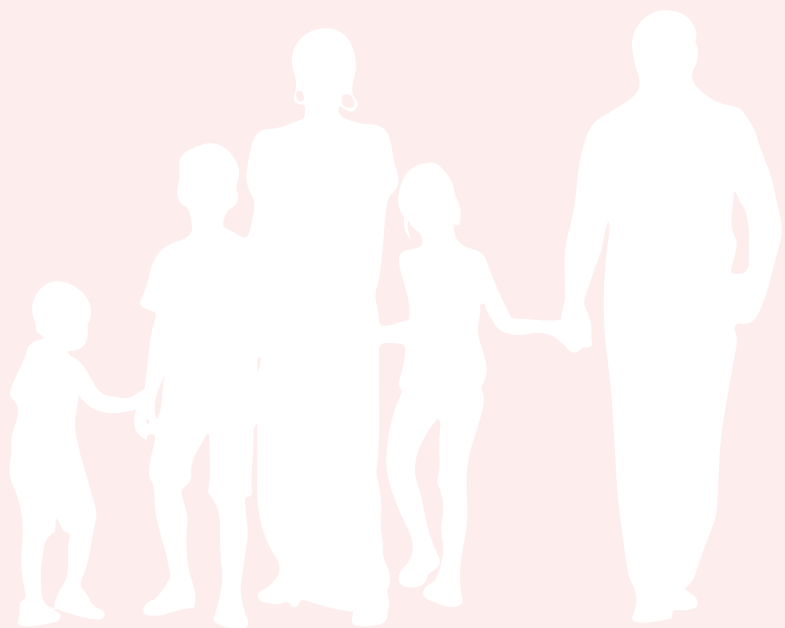
As a result, ILEP and its Members have focused increasingly on advocating for access by leprosy affected people to the services and supports that they need. In 2018, ILEP worked with the International Disability and Development Consortium (IDDC) and the Neglected Tropical Diseases Network (NNN) to advocate with the WHO and other policymakers for better disability services for those affected by leprosy.

We are finding that, although some aspects of leprosy are unique, much is gained by collaborating not only with one another inside ILEP, but also with likeminded organisations that are equally committed to preventing and reducing disability.

Better knowledge is also needed. In 2018, scientists and researchers from ILEP Members were involved in one of the Global Partnership for Zero Leprosy research subgroups that assessed the state of knowledge and the research priorities for disability prevention. Some also participated in a WHO consultation on earlier detection of nerve damage and better treatment of leprosy reactions – two leading causes of disability.

At the same time, one ILEP Member began to interact actively with the United Nations committee that assesses state compliance with the Convention on the Rights of Persons with Disabilities (CRPD). Because most of the committee's activities take place in Geneva, ILEP is well placed to support and expand this initiative in 2019, making states and policymakers increasingly aware of the disabling consequences of leprosy and their obligations, under the CRPD, to make the necessary provisions in all countries.

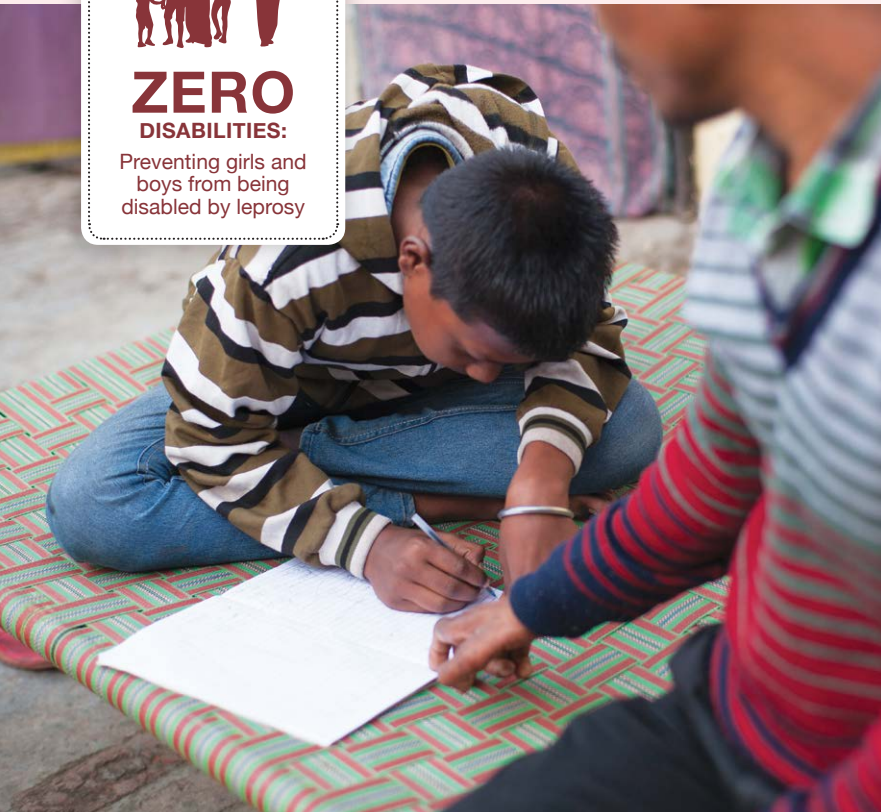
These global level activities complement the essential work ILEP Members are already doing at country and community level to promote the rights of persons with leprosy-related disabilities to rehabilitation and other services, to social inclusion, and to equality of opportunity.





ZERO DISABILITIES:

Preventing girls and boys from being disabled by leprosy



2

CASE STUDY: A family's challenge

When I was only fifteen years old, leprosy changed my life. I discovered a strange spot on my skin. I thought it would disappear with time. But it only got worse.

Then I also lost the feeling in my hands and feet. My family and the other villagers kept me at a distance. They would keep staring at my deformed hands and feet. They were afraid they would become affected with leprosy as well. My mother was the only one who didn't mind touching me and caring for me.

But then, suddenly, my mother died. I didn't know what to do without her. Everyone else loathed my presence. There was not a soul willing to help me. I felt so helpless and lonely that I decided to leave my village, afraid of all that I had to face.

It was only then that I went to see a doctor. He told me I had leprosy. He gave me medicines and treated the many wounds and ulcers I had contracted.

Ajay and his son Shivkumar doing homework (above) Ajay with others from his community (below).

© NLR LegHetVast

"You will find a leprosy colony in Amroha," he told me. "You can live there." And so I did. Where else could I go?

My wife, son, and I live an isolated life here, together with about thirty other families. I barely have the money to provide for my family. Every day I try to get a few rupees begging. I don't have a choice. Nobody wants to employ me because of my deformities. My greatest worry is the future of my thirteen-year-old son Shivkumar. He doesn't have leprosy, but he's discriminated against all the same. There is a chance he'll never get married. People don't want the child of a person affected by leprosy. They simply won't accept a marriage like that.

It's my dream that my son will never be forced to beg and will be able to build a better life outside the leprosy colony. I don't want him to go through the same misery I have gone through. He should not become the victim of my leprosy. I want him to pursue an education, as it gives him a better outlook for the future, but sadly that's out of my hands.

An ILEP Member reports that Ajay received training in self-care and his son Shivkumar will undergo vocational training.



ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices

ILEP takes the lead in cataloguing discriminatory laws, lobbying for change, and monitoring actions to amend or repeal them.

3

STRATEGIC GOAL: Towards Zero Leprosy Stigma

How things are

Stigma, discrimination and social exclusion have been a blight on the lives of leprosy affected people for millennia.

People affected by leprosy tell us that negative community attitudes like these can be the most troubling and the most disabling consequences of the disease. There is increasing evidence of the negative effects of stigma on mental wellbeing. Some countries including Bolivia, Egypt, India, Mali, Nepal, Pakistan, Sri Lanka and Thailand have discriminatory laws, a gross infringement on human rights.

Stigma is also a barrier to zero leprosy transmission because the fear of rejection often drives people to hide the disease rather than going for treatment.

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 are to be effective.

The UN General Assembly adopted 'Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members' in 2010, but traction for its implementation has been limited. The appointment in 2016 of Alice Cruz as the United Nations Special Rapporteur on leprosy, has slowly begun to increase awareness, especially within the human rights bodies of the United Nations, of the damage done by anti-leprosy discrimination.

How we are working for positive change

ILEP has taken the international lead in cataloguing discriminatory laws, lobbying for change, and monitoring actions to amend or repeal them. Our website shows the country locations and details of the 145 laws currently in place, and during 2018 ILEP Members were in the forefront of lobbying for change, especially in India where there is momentum to repeal more than 100 discriminatory laws.





ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices



Tackling discrimination goes far beyond the need to abolish discriminatory laws and practices. ILEP and its Members are working at various levels in countries, and also internationally, to encourage a rights-based and inclusive approach to ending leprosy stigma. During 2018 we began the process of strengthening and forming new relationships with human rights bodies in Geneva. We expect this work, including active support for the mandate of Alice Cruz, to be a major focus for the ILEP office in 2019.

A number of ILEP Member staff are involved in the Global Partnership for Zero Leprosy's subgroup proposing the research priorities on stigma and discrimination. ILEP Members are also involved in a Temporary Expert Group, established by the ILEP Technical Commission, to rewrite the ILEP Stigma Guides, taking into account new knowledge since these were first produced.

There will, in particular, be a stronger focus on the consequences of stigma on mental health, with strategies to prevent or mitigate negative effects on mental wellbeing.

The ILEP Panel of Women and Men Affected by Leprosy played an active role in 2018. Panel Members were leading representatives of persons affected by neglected tropical diseases (NTDs) in the annual NTD Network (NNN) conference, in NNN task-groups, and in bringing their vital perspective to work that has started on rewriting the ILEP Stigma Guides. Panel Members also worked on an ILEP policy on the participation of people affected by leprosy in key activities of the ILEP network, which is expected to be adopted in 2019.

By adopting a strong focus on discrimination, ILEP members strengthen their practices to promote social inclusion and end discrimination for persons affected by leprosy and their families.



ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices



3

CASE STUDY: Roses: a powerful weapon in the battle against stigma

Dr Sushil Koirala is known as ‘The Rose Doctor’. He has been a human rights and peace activist for more than 15 years and is the founder of the Rose Movement – a campaign to help bring peace and joy to others.

Dr Koirala first became involved with the leprosy community when he joined a TB and Leprosy Referral Centre run by a local NGO in Nepal. As he met more patients and was exposed to the difficulties they were facing, Dr Koirala decided to expand on his Rose Movement by promoting the exchange of flowers as a symbol of acceptance and solidarity as well as peace.

Why roses? Dr Koirala believes they best represent our diversity, yet our oneness, as human beings.

“While roses may be of different colours, a rose is still a rose... no matter what culture, language, colour, ethnicity, or religion we may come from or represent, we are all human,” he said.

Despite the thought out training programmes on stigma in HIV treatment, there was no such training on stigma in multi-drug resistant TB or leprosy in Nepal. In response, he began to use his roses as a tool to inspire others and begin the conversation about the social exclusion associated with these diseases.

“What we see... in leprosy is only the tip of the iceberg, this is just the manifestation of a large scale of stigma, discrimination and prejudice against various diseases, including mental health, disabilities and so on,” said Dr Koirala, who hopes that tackling health related stigma will soon be central to the international human rights agenda.

Dr Sushil Koirala with his roses in Nepal.

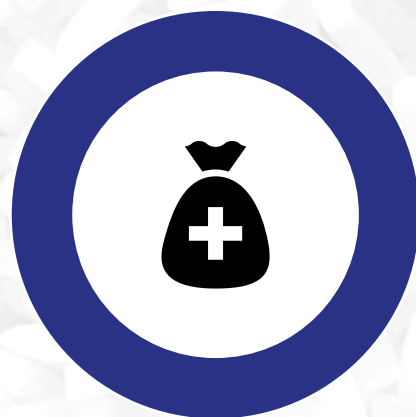
© Damien Foundation


A photograph showing a healthcare worker in profile, applying a white ointment to the cheek of a young girl. The girl is looking off to the side with a neutral expression. In the background, a young boy stands shirtless, and other people are visible near a body of water with trees in the distance.

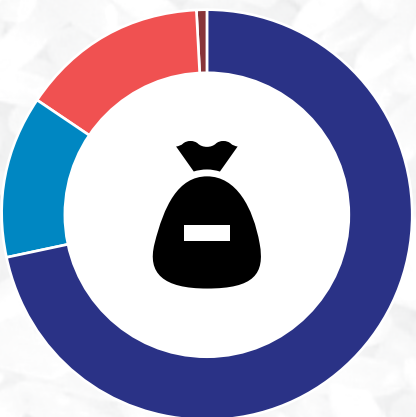
ILEP continues to focus on the stigma surrounding leprosy





FINANCIAL HIGHLIGHTS 2018

The following shows income and expenditure details in Swiss Francs (CHF). The audited financial reports are available. Please contact us for more information.



	Membership Contributions	496,089
	Total income (CHF)	496,089



	Staff costs	377,522
	Travel and meeting costs	66,979
	Administrative & Operating costs	78,324
	Taxes	2,965
	Total Expenditure (CHF)	525,790

The deficit for the year was funded from General Reserves.

United by a shared sense of responsibility and a common desire to improve the lives of people affected by leprosy and its consequences, ILEP and its partners recognise that through collaboration, co-operation and harnessing collective strengths, we will have a far greater impact in the fight against leprosy.



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