

ILEP ANNUAL REPORT 2017

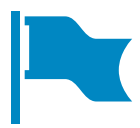


YEAR IN NUMBERS – at a glance



14

ILEP Members



66

Countries
we work in



700+

Projects



214,783

New cases
reported (WHO)



18,230

New child cases
reported (WHO)



2,428,840

Contacts screened
or examined in
countries where
ILEP is active
(ACS)



11

Countries with
chemoprophylaxis
or immunoprophylaxis
in their national
policies (ACS)



4,171

People affected by
leprosy with access to
wound care services
if needed (ACS)



82,862

People with leprosy-
related disabilities
that have access to
assistive devices in
countries where
ILEP is active (ACS)



18

Countries with
laws or policies
facilitating inclusion
of persons affected
by leprosy (ACS)



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

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INTRODUCTION – From the CEO

Tanya Wood, ILEP Chief Executive Officer



As we reflect on the past year, I am proud to see a number of successful collaborations and partnerships coming to fruition.

“I am delighted to report that a record 49 ILEP country coordinators responded this year!”

I am also reminded of the work that remains to realise ILEP’s true impact at scale. We have embarked on a journey to improve how we chart progress towards, and obstacles against, our ILEP Triple Zero Strategy. The main tool for this is our Annual Country Survey – I am delighted to report that 49 of our country coordinators responded this year!

This provides us with a valuable snapshot of what is happening in the countries where ILEP works, compared against the indicators we set in the ILEP strategy. It also, importantly, enables us to report on the NGO contribution to the London Declaration Scorecard.

We are extremely grateful to our ILEP country coordinators, as well as our members who have shared their data to update our **WWW map**.

This interactive map enables us to see the collaborative strength of the ILEP network at a global scale.

However, we know there are still challenges with this data. Therefore, ILEP has convened a working group on monitoring and evaluation (M&E). This group intends to continue the discussion on how we collect and analyse our data in a meaningful way, so we can see where we are making advances and where challenges remain. The M&E group will be critical as we move ahead, demonstrating ILEP’s work in the broader remit of the Global Partnership for Zero Leprosy.

A handwritten signature in blue ink, appearing to read 'Tanya Wood', with a long horizontal stroke extending to the left.

GLOBAL PARTNERSHIP FOR ZERO LEPROSY

Jan van Berkel, ILEP President



This year I was delighted to see ILEP's newly launched Triple Zero campaign gain momentum within our network and beyond.

"I am excited about the real opportunities that the Global Partnership opens up."

In addition to the strides we celebrated publicly, 2017 was important for the work that went on behind the scenes. The ILEP secretariat worked hard to ensure a stable foundation was laid for the Global Partnership for Zero Leprosy, ahead of its launch at the beginning of 2018.

ILEP played a strategic role in shaping the partnership, which brings together multiple stakeholders in an alliance that is bigger than the sum of all our individual parts.

With more than five decades of experience of collaborating with NGO members and other partners, ILEP is uniquely positioned to make a valuable contribution to the partnership. In turn, it will broaden our collaboration to include donors, persons affected, scientists, Ministries of Health and others.

The new partnership will coordinate action in three key areas, including accelerating research and strategies to interrupt leprosy transmission;

strengthening existing policies and practices at national and regional levels; and increasing advocacy and fundraising.

I am under no illusions that the path ahead will always be smooth, but I am also excited about the real opportunities that the Global Partnership opens up. Because of the excellent ground work done this year, I believe we are ready to seize opportunities for collaboration and overcome future challenges, as we work towards designing the roadmap towards Zero Leprosy.

Thank you to everyone who supported the development of this much-needed initiative, which will prove a milestone in our fight for zero leprosy.





ZERO

TRANSMISSION:

Stopping the
transmission
of leprosy

The World Health Organization's annual statistics on leprosy, published in September 2017, provide data about the current state of the disease from a record 143 reporting countries.

1

STRATEGIC GOAL:

Stopping the Transmission of Leprosy
– Towards Zero Transmission

The data tells us that global leprosy case detection has increased slightly. In total, 214,782 new leprosy cases were reported from 110 countries in 2016. This is up from 211,973 new cases reported in 2015.

The global statistics also reveal that 18,230 new child cases of leprosy were reported, a slight decrease on the previous year. ILEP's Annual Country Survey for this period shows that in 2016 the number of cases in children was 7.31 per million compared with 7.5 per million in 2015.

New diagnoses in boys and girls is significant because it indicates that leprosy is still being transmitted in communities, and that the disease has been transmitted relatively recently.

Looking at the long-term trend, we see that the number of new case detections is slowly decreasing but is stubbornly resistant to major change. It is clear that we need new strategies to help us dramatically influence this trend and bring down the transmission rates.

Strategies for Zero Transmission

ILEP members are adopting a number of important strategies to interrupt the spread of disease. This includes vaccine development and the screening of contacts of people who have been newly diagnosed.

A promising tool for interrupting transmission entered an important phase this year. In October, a leprosy vaccine candidate – developed by scientists at IDRI, with financial support from American Leprosy Missions – entered a Phase I clinical trial in human volunteers in the US.

The Annual Country Survey results show that in countries where ILEP members are active, almost 2.5 million people were screened or examined during this year. In addition, through administering preventative drug treatments to those in contact with people newly diagnosed with leprosy, there is the potential to further break the chain of transmission.



ZERO TRANSMISSION:

Stopping the
transmission
of leprosy

One project exploring this potential is “LPEP” – the Leprosy Post-Exposure Prophylaxis project – which is a collaboration between several ILEP members and external partners, including national leprosy programmes, Novartis Foundation and academia. Started in 2015, it has been running for three years, testing the feasibility and acceptability of a single dose of rifampicin in preventing the development of leprosy in those who have been in contact with people newly diagnosed.

The LPEP research programme is currently being implemented in eight countries (Myanmar, India, Indonesia, Cambodia, Tanzania, Nepal, Brazil, Sri Lanka) and is generating evidence that it is feasible to distribute a prophylactic treatment among the population at risk of developing leprosy by providing them with a single tablet of rifampicin.

While it is too early to demonstrate a significantly reduced risk of leprosy in the communities studied, preliminary results suggest a real boost to local leprosy control efforts.

This improvement in morale was reported by staff at different levels, from the primary health units to the central leprosy control coordination. This increased motivation was associated with the possibility of providing a preventive intervention. The study also found that the intervention was widely appreciated by the target population.

In November, stakeholders from the project including the ILEP implementing partners (Netherlands Leprosy Relief, GLRA, American Leprosy Missions and FAIRMED) met to discuss the study’s final steps. All countries developed plans to ensure effective integration of the LPEP activities into the routine leprosy control programmes in endemic countries.

These initiatives mean that ILEP members are well positioned to play a key role in the new Global Partnership for Zero Leprosy’s development of a comprehensive roadmap for accelerating efforts towards zero new cases of leprosy.





Gender inequality in leprosy endemic countries is one of the main barriers preventing women from accessing treatment. ILEP's social inclusion framework, developed in 2017, addresses the need to end the stigma associated with leprosy for women and girls.

© The Leprosy Mission Trust, India.



ZERO DISABILITIES:

Preventing girls and boys from being disabled by leprosy

ILEP members are working to prevent impairments from becoming lifelong disabilities, and to lessen the effect of those impairments.

2

STRATEGIC GOAL:

**Preventing Impairments in Girls and Boys
– Towards Zero Disabilities**

The ILEP Annual Country Survey 2017 provides useful insights into the importance of ILEP members' commitment to our second strategic goal of zero disabilities. Of the 49 countries which were able to report leprosy information, there were 12,608 people newly diagnosed with substantial visible impairments.

Such impairments and disabilities represent a very high cost to individuals, families and communities. When we consider that people who are diagnosed late are more likely to have passed on the infection, the cost is amplified even more.

These individuals join the millions already diagnosed with such permanent impairments, underscoring the importance of ILEP members' work in the area of disability, and that early case detection must be a key priority for leprosy services.

The survey also showed us that in some countries where ILEP is active in disability work, all or most of the people affected by leprosy who need wound care or self-care support have access to those services. This is a major accomplishment for those ILEP organisations. It also showed unfortunately, that for over half of the countries that provided responses, the lack of wound care and self-care services (or even awareness of such services) is minimal. In such situations, simple impairments can become devastating and permanent disabilities.

Strategies for Zero Disabilities

Improving social and community support and services for people affected by leprosy is key to preventing disabilities. Our Annual Country Survey shows that apart from a few countries where the ILEP members actively promote Community Based Rehabilitation (CBR), there are few such services available to people affected by leprosy. There is also very little awareness of this type of rehabilitation.





ZERO DISABILITIES:

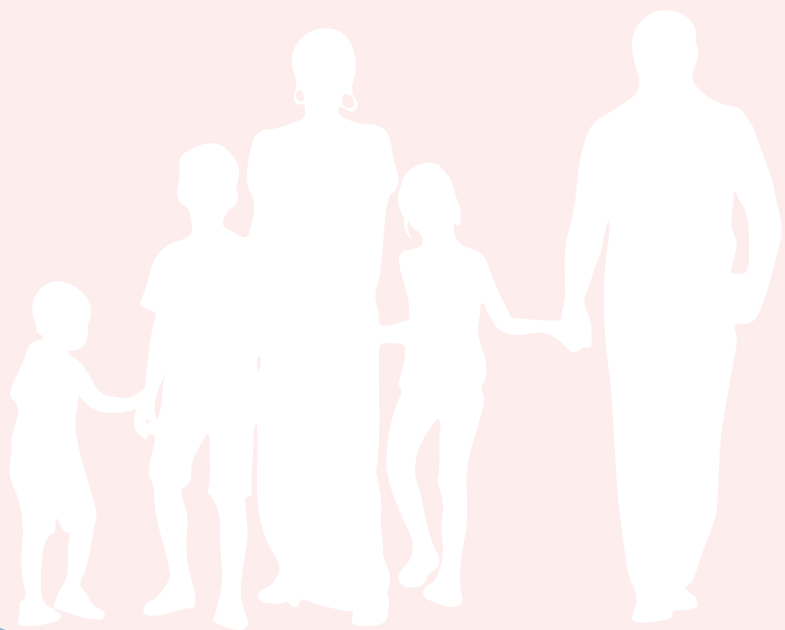
Preventing girls and
boys from being
disabled by leprosy

The survey shows that in countries where ILEP members are active, we are helping to prevent leprosy-related impairments from turning into disabilities through activities like surveillance, training in wound care, providing assistive devices and fostering CBR programmes.

However, it also shows that the need for services is far greater than what we can currently meet.

In 2017, ILEP worked with the International Disability and Development Consortium and others, advocating to the WHO and other bodies for enhanced disability services (including CBR and self-care), to benefit people affected by leprosy. This advocacy is vital as key players in the development world increasingly focus on Universal Health Coverage and new models of rehabilitation.

We must make sure the needs of people affected by leprosy are not ignored. Across the ILEP federation, practical work with individuals and communities, as well as more strategic advocacy, drive towards the same goal: making sure that leprosy-related impairments do not turn into lifelong disabilities.





ZERO DISABILITIES:

Preventing girls and
boys from being
disabled by leprosy

LEPRO INDIA
health in action



Sakshi was just ten years old when she noticed the first sign of leprosy. Her hand became numb and she had trouble gripping her pencil. Her classmates noticed and started bullying her, calling her "lulli", a derogatory term for someone who is disabled. Eventually she stopped going to her local school in Bihar, India, as she could not keep up with her work. Following her diagnosis at the Lepa-run Munger referral centre, and a 12 month course of multi-drug therapy, she has no lasting disabilities.

Image © Lepra.

2

CASE STUDY:

Preventing leprosy in children: global push needed!

Sakshi's story is all too common across the world in poor and marginalised communities where pockets of the disease remains endemic. In 2017, the WHO reported a total number of 18,230 new child cases of leprosy. This is roughly 9% of the total number of global cases reported annually.

Worryingly, reports in some countries have found that about 11% of children already have visible impairments at the time of diagnosis, indicating late detection. Given that the bacillus, *Mycobacterium leprae*, multiplies very slowly and is only mildly infectious, children are most likely to contract leprosy at home, from close and prolonged contact with an infectious person. Research tells us that if you live in a household with a person who has untreated leprosy, you have an 8-fold increase in the risk of getting leprosy yourself, compared with the general population.

Post-exposure prophylaxis is a promising treatment strategy that could help drive down the number of children contracting leprosy.

While globally great strides have been made to reduce the incidence of leprosy, more than half of the countries reporting leprosy cases documented

cases in boys and girls under 15 years old. The widespread nature of this disease indicates that a coordinated international response is required.

Children as young as nine are presenting with multiple impairments, including clawed hands and foot drop, and are needing reconstructive surgery and physiotherapy to recover.

Gruelling medical interventions aside, children with leprosy often face crippling social barriers, including the loss of education, bullying and sometimes rejection by family members because of the stigma associated with this disease.

If we are to bring child leprosy rates down, the global health community must work with national governments to strengthen health care systems, improve early case detection and expand preventative treatments.

We must ensure that adults diagnosed with leprosy complete their treatments properly to stop the disease spreading in households. We must also get serious about ending discriminatory laws and practices, and increasing participation of people affected by leprosy, something ILEP members are committed to.



ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices

Ending discriminatory laws and practices and promoting the inclusion of persons affected by leprosy is ILEP's third strategic goal.

3

STRATEGIC GOAL:

Promoting Inclusion – Towards Zero Discrimination

This is a challenging goal to make and measure progress on – but also one we acknowledge to be vitally important in our work to achieve zero leprosy.

The depth of this challenge is reflected in the conflicting data we find in response to different surveys and questionnaires. In some cases, discriminatory laws and practices impact heavily on persons affected and are clearly evident. In other cases they are more subtle, but still a gross infringement of human rights. ILEP's Annual Country Survey highlighted that we need to step up our efforts to repeal discriminatory laws in countries such as Nepal, Sri Lanka, India, Egypt, Pakistan, Thailand, Mali and Bolivia.

We were pleased to note that a substantial number of countries now have newly drafted laws or regulations that specifically facilitate the inclusion of persons affected by leprosy.

Gender inequality is one of the main barriers that prevents women and girls with leprosy from accessing treatment. In 2017, ILEP members provided an overview of their work on gender,

identifying some key considerations for tackling gender differences in programmes, while also acknowledging the challenge of ensuring women are in leadership positions within their own organisations. The report can be found [here](#).

Gender remained on the agenda throughout the year. Academic expert Sally Tehobold lead a challenging discussion on why data disaggregation matters at the ILEP October meeting. Mary Varghese facilitated a thought-provoking discussion at the Neglected Tropical Disease (NTD) NGO Network (NNN) conference on why gender matters in leprosy.

In October, ILEP welcomed the appointment of Alice Cruz as the new Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. The mandate was created in 2016 by the United Nations Human Rights Council, thanks to high level advocacy from The Nippon Foundation and the support of several ILEP members and partners.

In India, lobbying by The Leprosy Mission Trust of India helped lead to the introduction of the Private Members Bill addressing the issue of discrimination and exclusion of people affected by leprosy.



ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices

This bill was filed by Member of Parliament, Mr. K T S Tulsi and aims to repeal the 119 discriminatory laws relating to persons affected by leprosy. It builds on the EDPAL Bill, covering more laws and including the creation of an ombudsman.

Strategies for zero discrimination

Tackling discrimination goes far beyond the need to abolish discriminatory laws and practices. The ILEP secretariat and members are working at various levels in countries and internationally through human rights bodies in Geneva to encourage a rights-based and inclusive approach to ending leprosy.

Building participation of people affected by leprosy in key activities of the ILEP network is an important guiding principle.

In 2017, the ILEP Panel of persons affected advised the Members' Assembly on a number of issues including communications. The Panel proved their importance beyond ILEP – for example, by providing strategic input in the WHO Leprosy Treatment Guidelines and through their prominence at the NTD Summit.

In 2017, ILEP launched its Social Inclusion Framework, which targets our attention on:

- **Strengthening the role of persons affected.** The role of the Panel has expanded within ILEP and more broadly, to engage with NNN task groups and the WHO Guidelines process.

In future we will continue to strive for greater representation of persons affected by leprosy across ILEP members' own organisations.

- **Gender.** We continued to foster the disaggregation of data in endemic countries and also to improve disaggregation in our own data collection. Gender has been included in our country planning initiatives, with a specific focus of ILEP-related monitoring and evaluation. We plan to continue this work by identifying instances of best practice relevant to leprosy.
- **Ensuring inclusive access to services.** ILEP and key member staff have strengthened their role in informing global models of disability and healthcare services. We advocated on leprosy concerns in international forums on communicable diseases. We will continue to advocate strongly for the inclusion of persons affected in disability, rehabilitation and universal health frameworks and practice.
- **Tackling discriminatory practices and legislation.** We have built strong alliances with the Special Rapporteur for zero leprosy, advocated in proceedings of the Office of the High Commissioner for Human Rights, and engaged with key leaders to bring about change.

By adopting these strategies, ILEP members will strengthen our own practices relating to social inclusion as well as our lobbying efforts to promote inclusion and end discrimination for persons affected by leprosy.





ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices



Kishori Yadhav is a man who leads a self-help group that provided non-formal education for Dalit women. As well as increasing social participation, the project demonstrated that self-help group membership can also impact on household wealth.

Patili Maya and the other members of Ranichuri self-help group repaired a road to give village children easier access to the local government school. Because she is affected by leprosy, Patili Maya had formerly been castigated for using that same road.

Images © Rowan Butler.

3

CASE STUDY:

Reaching the unreached: tackling stigma and poverty for people affected by leprosy in Nepal

Kishori Yadhav was once ostracized for having leprosy. Now he enjoys respect in his community because he leads a self-help group that organised basic literacy training for Dalit or “Untouchable” women.

Leprosy is still endemic in some of Nepal’s poorest communities. It perpetuates poverty and disability, and stimulates negative attitudes among others which prevents affected people, especially women, from participating socially.

Establishing self-care groups, which then become self-help groups, is known to increase members’ social participation and to reduce stigma.

Patili Maya, a woman affected by leprosy, and her self-care group repaired a road so that children could get to school easier; she herself once had to fight discrimination to be allowed to use the road.

The RECLAIM project implemented by the Nepal Leprosy Trust with support from American Leprosy Missions, tracked the impact group membership also had on poverty.

Assessment of 50 groups (866 people) revealed that most voluntarily became involved in community development activities. Using a measure of household wealth it was also found that after three years the shift to greater household asset ownership for group members was significant.

The project showed that self-care group membership can lead to improved social inclusion and more productive living.



A version of this case study was published in the Uniting to Combat NTD's 5th assessment report, Nov 2017.



WORLD LEPROSY DAY 2017

Commemorated annually on the last Sunday in January



Poonam with doctor
in more recent years

Observed on 29 January 2017, the theme of **World Leprosy Day** was Zero Disabilities in girls and boys affected by leprosy. This theme highlights that when children contract leprosy, but are not diagnosed early enough, they experience a lifetime of disabilities and other impacts of the disease that could otherwise have been prevented. Unfortunately, this happens in thousands of cases.

Through sharing the stories of children who are affected by leprosy, like Poonam from Madhya Pradesh, India, we helped raise awareness of how this disease continues to affect boys and girls, and advocate for change.

Poonam's story demonstrates the importance of early detection, intervention and treatment, on the quality of someone's life.

ILEP used World Leprosy Day 2017 to call for more active detection and early diagnosis, to help achieve our goal of zero disabilities in girls and boys. We made the case for special attention to target highly endemic countries and highly endemic pockets within countries. We demonstrated that by working together, we can stop transmission, prevent disabilities and end discrimination of people affected by leprosy.

To support members' activities, the ILEP secretariat prepared a range of materials for local adaption and use, including media materials, case studies and a quiz to drive social media engagement. An op-ed from Tanya Wood was also published in the **Huffington Post**.

This year, a highly successful social media "Thunderclap" event was coordinated – a means of collectively making a splash on social media by releasing a single message through numerous sources at one time. More than 130 supporters signed up – reaching an estimated 170,000+ social media accounts.

Thanks to all our members, partners and friends for helping to raise the profile of leprosy and demonstrating support for our call to end disabilities in children with leprosy.

Poonam's story

When Poonam was 13, she began to notice dark patches of skin on the side of her neck that soon spread to 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 the diagnosis of leprosy. Soon after, Poonam started a course of MDT and received reconstructive surgery on her hand.

WORKING WITH THE NTD COMMUNITY

Leprosy is an officially recognised Neglected Tropical Disease (NTD)

*Projet de Lutte contre
l'Ulcère de Buruli
Région Maritime, TOGO*

In many of the countries where we work, leprosy is often detected alongside one or more of the NTDs. The leprosy community faces many shared challenges with other NTD NGOs, health agencies and development organisations, which provide services and health care for hard to reach and marginalized communities in endemic countries.

ILEP can provide both leadership as well as learn from others working in the broader field of NTDs. During the NTD Summit held in April in Geneva, ILEP and people affected by leprosy played a key role. Evelyn Leandro, a person affected from Brazil, was on a panel with Bill Gates at the pre-summit; Kofi Nyarko

presented Margaret Chen, Director-General of the WHO, with a recognition gift; Dr Zoica Pereira, a psychologist, shared her personal story; and Mathias Duck was on the panel for the closing plenary, bringing attention to the need for more inclusivity of persons affected in the fight against NTDs.

ILEP was involved in leading a number of sessions including a well-received event which helped to make the link between mental health and NTDs and a joint session with other NTD groups to look at skin care issues.

During 2017 we continued to deepen our relationship with the NNN, with ILEP CEO Tanya Wood taking on the role of Chair of the NNN at the Dakar meeting in September. Rosa Argent, ILEP Comms Manager, became the NNN communications lead.

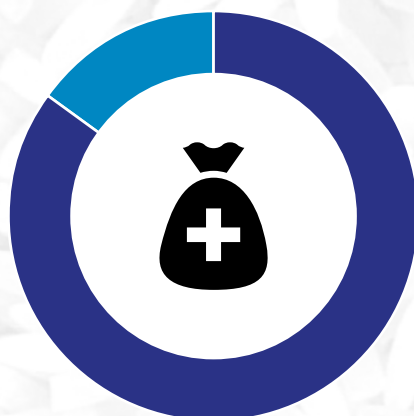
There is strong alignment between the NNN's BEST framework, which informs practice across the NTD community in the areas of Behaviour, Environment, Social inclusion and Treatment and care, and the ILEP Triple Zero campaign strategy, which focuses on ending leprosy through zero transmission, zero disabilities and zero discrimination.



Image: ILEP members often work with governments on national leprosy programmes. Together with the Ministry of Health, DAHW set up a nationwide programme for leprosy control, which has since developed into the combined national programme for leprosy and Buruli ulcer. © Jörg Nitschke.

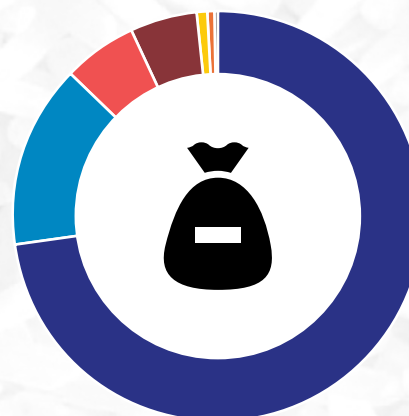
BUDGET HIGHLIGHTS








For the year ending 2017

The following shows income and expenditure details in Swiss Francs (CHF) on the 2017 budgets which were approved by the Members' Assembly. The audited financial reports are available.

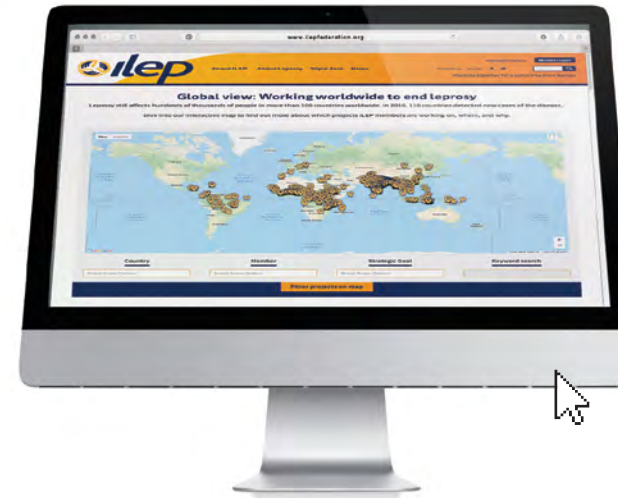


	Membership Contributions	496,423.47
	Additional approved Income	88,845.00
	Total income (CHF)	585,268.47



	Staff costs	431,021.98
	Travel and meeting Expenses	85,723.61
	Operating Expenses	35,423.84
	Administrative expenses	30,925.37
	IT Support expenses	6,527.23
	Taxes	3,230.35
	Bank costs	1,776.89
	Total Expenditure (CHF)	594,629.27

Our members work with girls and boys, women and men affected by leprosy; with Ministries of Health and the World Health Organization; with other NGOs in the health and development sectors; with the Novartis Foundation, The Nippon Foundation and other philanthropic trusts; and with the support of some 500,000 individual supporters.



ILEP MEMBERS

American Leprosy Missions
Associazione Italian Amici di Raoul Follereau
Austrian Leprosy Relief Association
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 Memorial Health Foundation
The Leprosy Mission International



International Federation of Anti-Leprosy Associations
Quai de L'île 13, 1204 Geneva, Switzerland
officer@ilepfederation.org