



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

ILEP ANNUAL REPORT 2020



YEAR IN NUMBERS – at a glance



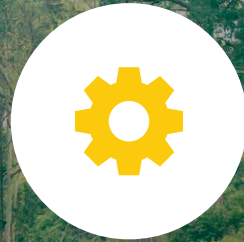
13

ILEP Members



62

Countries
we work in



484

Projects in
1028 locations



202,189

New cases
reported (WHO)



10,813

New cases with
grade-2 disabilities (WHO)



14,981

New child cases
(WHO)



78,625

New female
cases (WHO)



3-4 million

Persons living
with visible
disabilities (WHO)



~30 million

People at
risk of
leprosy (WHO)



130

Discriminatory
laws
worldwide

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

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PRESIDENT'S REPORT

Brent Morgan, ILEP President



Staying strong through the pandemic

“Through a time of unprecedented global crisis, the ILEP partnership has remained strong.”

The Covid-19 pandemic has had a profoundly damaging effect on the work of ILEP members, and on the lives of people affected by leprosy.

Many ILEP programmes, especially those involving outreach into the community, stopped. Deliveries of MDT, the essential drug therapy for new patients, were interrupted. In many areas, registrations of new patients were down 60% or more – and those delays in diagnosis and treatment increase the likelihood of leprosy transmission and disability. Leprosy self-care and self-help groups, which are many people's lifeline of mutual support, mostly stopped, as did rehabilitation programmes.

At the same time, people affected by leprosy – often the poorest and most left-behind in their communities – were being especially impacted by the consequences of the pandemic. Social protection measures and government aid were often less accessible to people with disabilities and people stigmatised by leprosy.

ILEP members responded. They reoriented laboratories and hospitals to include Covid-19 diagnosis and treatment.

They provided humanitarian aid, advocated for those in need, and supported local and national organisations of people affected by leprosy. They adapted and innovated, using mobile phones, SMS, social media and other digital means to stay connected and support people remotely. Use of digital technologies has had such an impressive effect that it will permanently change the way many teams work, both during and after the pandemic.

The pandemic experience has again illustrated the value of partnership. ILEP member CEOs started meeting monthly, to share experiences and to learn from one another as they responded to what was happening around them. Through a time of unprecedented global crisis, the ILEP partnership has remained strong. We know we will not defeat leprosy on our own, but together and with partners worldwide, we can achieve our goal of a world free from leprosy.

A handwritten signature in blue ink, reading "Brent J. Morgan". The signature is fluid and cursive, with a large initial "B" and "M".



MESSAGE FROM THE CEO

Geoff Warne



Learning in a time of crisis

“Online interactions give us opportunities to learn together, build trust and identify new opportunities for collaboration towards our ultimate goal of zero leprosy.”

One of the ways ILEP members strengthen our partnership is through learning together. We planned a face-to-face conference in 2020 about digital innovation and leprosy expertise, but due to the Covid-19 pandemic we switched to a Zoom conference – with startling benefits. Instead of 50 participants, we had 190, most from leprosy-endemic countries. The mutual learning, and the powerful input by working groups on the subject of rebuilding leprosy expertise, were impressive. They challenged our assumption that the best learning is when physically together.

This has also been a year of learning in our worldwide programmes. Repeatedly, we have heard accounts of staff teams responding creatively to lockdowns and other restrictions. Social media and mobile phones have enabled our people to keep in touch and support one another, and to reach out to people affected by leprosy and their family members to provide health advice, encouragement and a listening ear. That has challenged our assumptions about how we can tackle some aspects of our work in leprosy.

Engagement with the World Health Organization (WHO) and the UN human rights bodies – where ongoing advocacy from ILEP are crucial – has also switched to digital platforms. Likewise our participation in the Global Partnership for Zero Leprosy and in the neglected tropical disease (NTD) and disability consortia that ILEP interacts with. We prize human contact and hope to meet face-to-face again, but we value what the communication technologies offer us.

We will build on these learning experiences in 2021. Online platforms will give us opportunity to learn together, formally or informally, through the current issues that face us. These and our other regular interactions build trust and can lead to new opportunities for learning and collaboration towards our ultimate goal of zero leprosy.

A handwritten signature in blue ink, appearing to be 'G. Warne', located at the bottom right of the page.





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





ZERO
TRANSMISSION:

Stopping the
transmission
of leprosy

Backlogs of untreated cases of leprosy were a major concern at the end of 2020, and ILEP members are planning how to cope with the backlog alongside the regular activities of 2021.

1

STRATEGIC GOAL: Stopping the Transmission of Leprosy – Towards Zero Transmission

How things are

The number of new cases of leprosy per year has hardly changed over the past decade.

In the next five years, another million people will catch the disease, with all its multitude of consequences for the individual, family and community. Chronic barriers to ending leprosy transmission include lack of skills and tools to aid diagnosis, low community awareness of leprosy symptoms, weak case-finding and contact tracing programmes, and stigmatisation: people fear being labelled with leprosy and are therefore reluctant to get diagnosed or seek help.

Dwindling leprosy expertise, including clinical skills at all levels, is a chronic challenge identified by almost every endemic country government. Current approaches to leprosy training are inadequate, and the issue is compounded by inadequate national budgets for training. Research gaps are another major concern. Research into more effective active case detection, improved preventive approaches or diagnostic tests for infection or disease could produce breakthrough applications.

During the Covid-19 pandemic, efforts to stop leprosy transmission were set back. Governments had different priorities, and lockdowns and travel restrictions meant that case-finding activities and contact tracing were curtailed. There will be a backlog of new cases into 2021, with the likelihood of ongoing transmission. Problems with the supply of multidrug therapy have aggravated the picture: in some countries, people were not able to get leprosy treatment for prolonged periods.

How we are working for positive change

One of ILEP's primary roles, working alongside national leprosy programmes, is as a source of expertise. During 2020, ILEP held an online international conference aimed at tackling the worldwide problem of building and maintaining leprosy know-how.

During 2021, ILEP will push forward with developing a response plan which can be tested and rolled out in both higher and lower endemic areas. The plan will include attention to expertise within ILEP, as well as within government programmes.





ZERO TRANSMISSION:

Stopping the
transmission
of leprosy

At country level, ILEP members work closely with governments and other partners to advise on and model active case-finding and contact-tracing programmes. In some places, ILEP members supplement the work of governments by running case detection activities, especially in hard-to-reach areas. Several members associations are working with governments to implement and evaluate the efficacy of post-exposure prophylaxis programmes as a contribution to leprosy prevention. In many countries, leprosy activities are integrated with other skin diseases, and this integration is likely to accelerate in line with the new WHO Neglected Tropical Diseases Roadmap 2021-2030. ILEP members strive to ensure that programmes are attentive to reaching women and girls, people in more remote communities, and others at risk of being missed or excluded.

Backlogs of untreated cases of leprosy were a major concern at the end of 2020, and ILEP members are planning how to cope with the backlog alongside the regular activities of 2021. ILEP is especially concerned about the frequent instances in 2020 when MDT was not available, and is interacting with WHO and Novartis, which donates the drugs, to ensure this does not happen again.

Most ILEP members invested in research during 2020, 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 projects during the year. Clinical trials into LepVax, a potential leprosy vaccine, were delayed in 2020 but are set to resume during 2021-2022.

The ILEP Technical Commission, ILEP's leading expert advisory body on leprosy, was reorganised during 2020. After wide consultation it will agree on a new workplan in the first quarter of 2021, with a priority on dealing with technical issues on which there is a lack of expert guidance, or where the current guidance is obsolete. The resulting products will be relevant not just to ILEP but to the entire leprosy world.





ZERO TRANSMISSION:

Stopping the transmission of leprosy



1

CASE STUDY: Bijanu Mikobi

Bijanu lives in Bulape-cité in a forested area in Kasai province of the Democratic Republic of the Congo. Hunting and agriculture are the main occupations in this generally poor area.

Bijanu was first diagnosed with leprosy aged 32, and as far as she was concerned, this was a catastrophe.

“For me, the problem started a pale spot on my right foot. At the time, I was working in the fields and was also a saleswoman at the local market. The spot spread, there were more and more, and they began to become troublesome. This situation made me worried because I did not know how to explain what was happening to me. Eventually I consulted the nurse at the health centre in my village, and she confirmed that I had leprosy.

I was utterly shocked. I was immediately convinced that I was going to lose my toes and my limbs. I also dreaded my husband’s reaction.

I was wondering if I would continue to live with my children at home, and if I would still have customers to buy items at the market. So many questions came into my mind.

But the nurse reassured me and gave me multi-drug therapy, which is free of charge. I found that I was able to lead a normal life and even at the market, I continued my sales activity and people kept buying my items without problem. Leprosy awareness in the community has contributed a lot to that. But I am thankful to the donors who support this project which is strengthening the community local health system in Kasai. It has allowed my leprosy to be detected early and enabled me to avoid disabilities that could be a serious handicap in my life.

My advice to anyone else who is diagnosed with leprosy is to take the treatment correctly and to follow the advice of the nurse and community health workers.”

First published by ILEP member effect:hope and used with permission

After the shock of being diagnosed with leprosy, Bijanu has found that, thanks to early diagnosis and prompt treatment, she is able to live a normal life with her family and as a vendor at the local market.

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**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

Leprosy-related impairments represent a very high cost to individuals, families and communities, and are estimated to affect the lives of at least 3-4 million people alive today.

2

STRATEGIC GOAL: **Preventing Disabilities from Leprosy** **– Towards Zero Disability**

How things are

Leprosy-related impairments represent a very high cost to individuals, families and communities, and are thought to affect the lives of at least 3-4 million people alive today. Leprosy 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. Due to lack of expertise, people with leprosy complications may not be properly assessed or treated. Even where the risk of complications is recognised, there is often limited access or referral to essential care services including reaction management, reconstructive surgery, wound care and the provision of assistive devices.

Self-care training to prevent disability, physical and socio-economic rehabilitation, and counselling and psychological first aid are all important services for people experiencing nerve damage or leprosy-related impairments.

During the Covid-19 pandemic, many of these services were suspended, and ILEP members are concerned that the rate of physical damage to hands, feet and eyes may have increased during those months. The activity limitations that result from this damage can rob people of their livelihoods and cause difficulties in the normal daily activities of life.

How we are working for positive change

Several ILEP Members are involved in the provision or support of leprosy referral services, such as specialist hospitals, in endemic countries. Typically, these facilities can manage reactions, offer wound care, deal with other complications such as damage to the eye, supply assistive devices along with training and advice on self-care, and offer reconstructive surgery with associated physiotherapy services.





ZERO DISABILITIES:

Preventing girls and boys from being disabled by leprosy

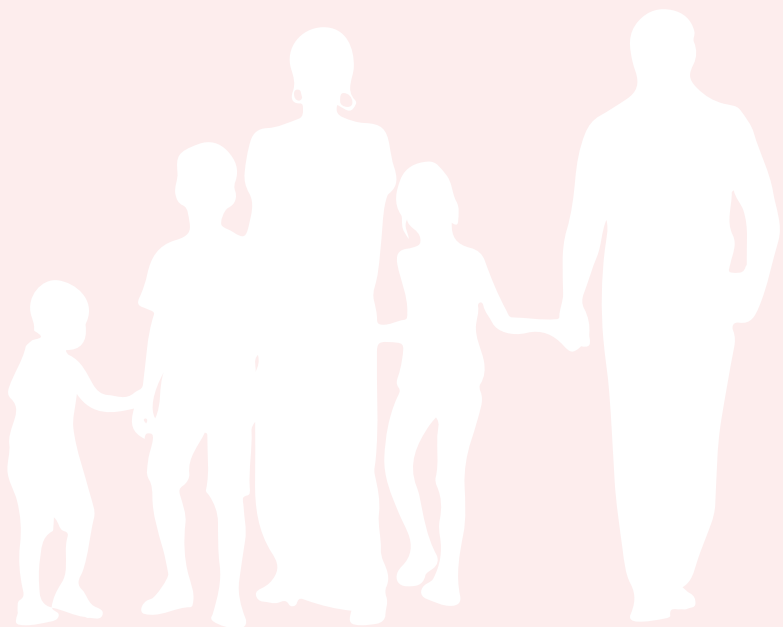
Some ILEP Members support government programmes in supplying footwear that helps a person with no feeling in the feet to avoid damage when walking.

Taking a person-centred approach, ILEP members are often involved in helping persons at risk, and their family members, to understand about the signs of possible nerve damage and to do the right daily exercises and make suitable lifestyle modifications in order to reduce injuries and protect limbs and eyes. In some countries, ILEP members are involved in the formation of self-care groups in the community, which include people suffering not only from leprosy but also from other conditions needing self-care.

ILEP members are also very aware of the how leprosy can affect people's mental wellbeing, and advocate for the provision of simple psychological first aid at primary and secondary health centres.

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. In many communities, self-help groups of people affected by leprosy, and sometimes other marginalised people, have had a powerful effect in encouraging solidarity and also enabling new livelihoods through small savings and loan schemes. In some countries, these groups have amalgamated regionally to form powerful forums for self-advocacy.

At the international level, ILEP engaged actively in 2020 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. During the year, ILEP made or supported submissions on human rights and leprosy in Indonesia, Angola, Bangladesh and China.





ZERO DISABILITIES:

Preventing girls and boys from being disabled by leprosy



2

CASE STUDY: Rahmawati

Rahmawati, who is currently 29, is a leader of the South Sulawesi branch of PerMaTa, an organisation of persons affected by leprosy working in three out of Indonesia's 34 provinces.

She was diagnosed with leprosy at the age of eleven when she was in the fifth grade of elementary school. Her left leg became paralyzed and she spent three years in bed. She was eventually cured but stayed at home because she was ashamed of the scars left on her skin.

When Rahmawati was 21, a branch of PerMaTa was established in the Gowa district of South Sulawesi and she began to participate in its work. In particular, she became interested in actions to educate school children and the community about leprosy, and through her involvement she was able to open up to people around her.

Rahmawati says that while leprosy prevented her from continuing her studies, she has precious friendships through her activities with PerMaTa and has gained a lot of knowledge and experience. She can now openly tell people that she is a person affected by leprosy.

This project also demonstrated her positive spirit and leadership qualities. In one village she visited, she said the community leader had been surprised by her can-do attitude. But as she explains it:

"I want to contribute to improving the lives of as many persons affected by leprosy as possible who are facing difficulty during the coronavirus pandemic. Even a little support can help them to get through it. And I want to support those who, like me, have experienced stigma and discrimination as a result of leprosy."

First published by ILEP member Sasakawa Health Foundation and used with permission.

'I'm cured' says the placard. Although Rahmawati suffered adverse health consequences of leprosy, she now speaks publicly with confidence, shows a 'can-do' attitude and supports people who have had similar experiences to hers.

© Sasakawa Health Foundation





ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices

National organisations of persons affected by leprosy, many supported by ILEP members, continue to emerge and work together as an empowered force for change.

3

STRATEGIC GOAL:

Promoting Inclusion of People affected by Leprosy – Towards Zero Discrimination

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.

One symptom of the prevalence of stigmatising attitudes is the presence of discriminatory laws. More than 20 countries keep such laws in force against persons affected by leprosy, and it is an ongoing challenge to get them amended or repealed.

In theory there are protections against discrimination. The United Nations Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members form an excellent guide for governments on how to assure the human rights of persons affected by leprosy. But in order to have effect, they need to be incorporated into countries' general human rights protection frameworks.

How we are working for positive change

During 2020 ILEP continued to take the lead in cataloguing discriminatory laws. At year-end, 130 laws remained in place, marginally down on 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.

We are seeing the beginnings of momentum for change especially in India, where more than 100 discriminatory laws remain.





ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices



Early in 2020, ILEP and the NGO Neglected Tropical Diseases Network (NNN) co-published a set of Stigma and Mental Wellbeing Guides, which apply to a range of stigmatising health conditions including leprosy. These were published on the web in such a way as to enable people to digitally translate and download them, whether to use them for training or to put them into practice in their daily work.

National organisations of persons affected by leprosy continued to emerge and work together as an empowered force for change, in 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 and would like to see them flourishing in all leprosy-endemic countries. The ILEP Advisory Panel, and the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, have played a valuable role in enabling these organisations to increasingly speak for themselves.

ILEP actively supported the re-appointment of Alice Cruz, the Special Rapporteur, for a further term, and will develop new means of cooperation with her in 2021.

In 2020, for the first time, two national organisations of persons affected by leprosy – Brazil and Sierra Leone – made direct submissions to the UN human rights mechanisms on the reality of discrimination and social exclusion in their countries. ILEP also continued to make or support submissions to the UN Committees for Elimination of Discrimination Against Women (CEDAW), the Child Rights Committee (CRC) and the Universal Periodic Reviews of countries' human rights record. There were submissions on Vietnam, Nepal, Myanmar, Indonesia and Mozambique. These submissions contribute to keeping the reality of leprosy on the radar of the United Nations, and complement advocacy by ILEP members in-country to bring human rights abuses to an end.

The ILEP Advisory Panel, which consists of women and men with personal experience of leprosy, was re-elected in 2020 and expanded to seven persons residing in six countries. The Panel acts as an essential conduit to people's organisations in many other countries. Through these connections and the direct engagement of Panel members, ILEP's decisions continue to be influenced by the voice of persons affected by leprosy.



ZERO DISCRIMINATION:

Abolishing
discriminatory laws
and practices



3 CASE STUDY: Venancio

Venancio was working in a timber yard in 1985 when he started noticing symptoms of leprosy. His company was good to him and took him to the provincial capital, Pemba, so that he could receive treatment.

Unfortunately those were the days of the civil war in Mozambique and, although Venancio received some treatment, he didn't realise that the treatment was incomplete. He eventually lost his job in the timber yard due to being unwell. He went back to his village to take up subsistence farming, but his leprosy symptoms came back. He lived with ulcers in his feet and eventually lost his fingers.

In 2004 he met members of ALEMO, the Mozambican association of people affected by leprosy. They encouraged him to restart treatment. As a result, his leprosy was cured but its disabling effects have stayed with him. Meeting ALEMO has been a significant moment in his life.

Venancio is overcoming the economically disabling effects of leprosy by learning better farming techniques, participating in a savings programme and leading an active organisation of people affected by leprosy in his village.

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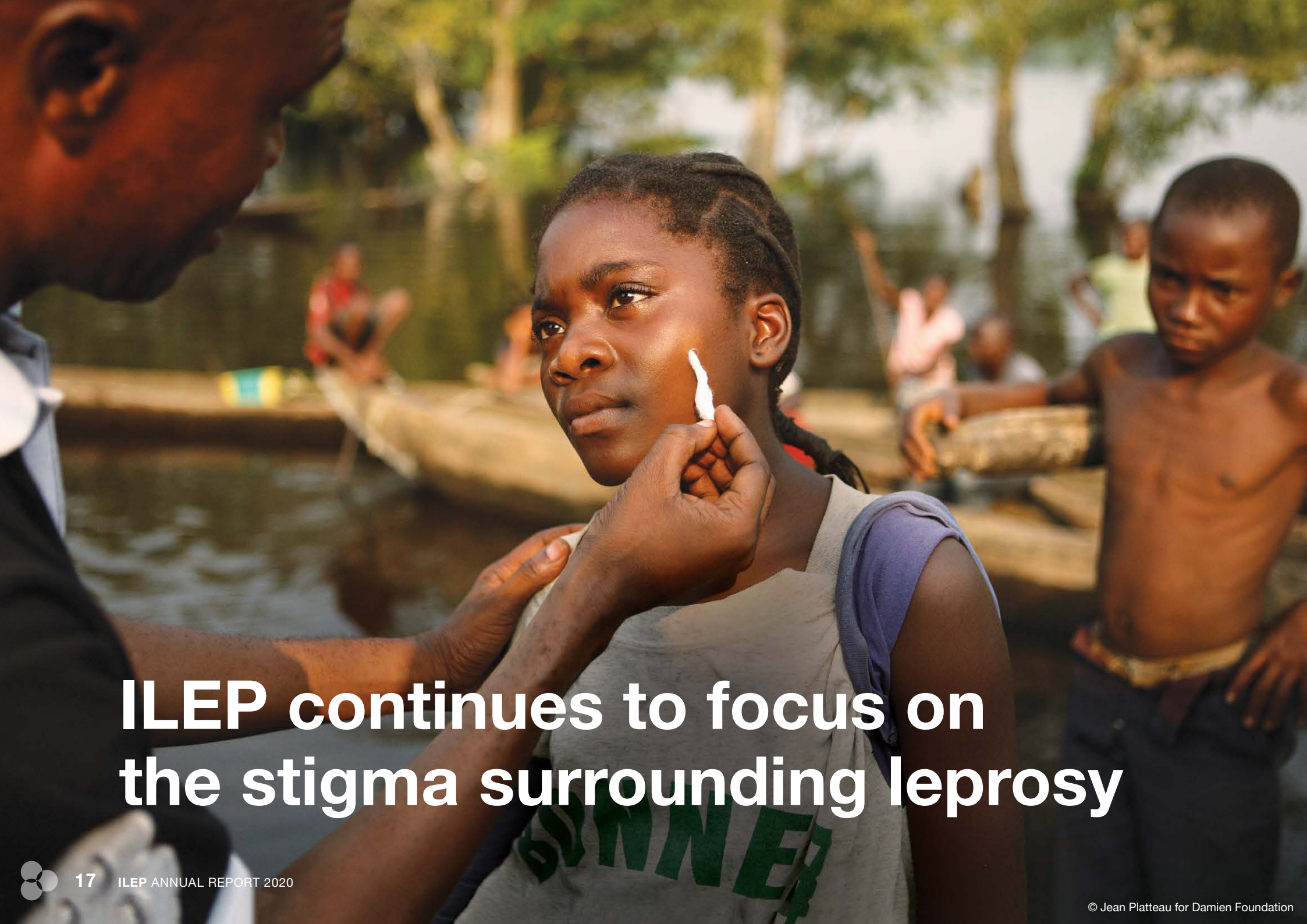
He started organising people in his village as ALEMO members: the group has grown from five to 39, and the stigma and discrimination associated with leprosy in his village have disappeared.

Venancio has also benefitted from enrolment in The Leprosy Mission's Livelihoods and Food Security Project in Katapua. Until that project he had been using traditional farming methods, which led to loss of crops and a low-quality yield. At the training he learnt about mulching and not burning the field, planting in rows, and thinning the plants. He joined the savings group, which encourages him to set aside some of his income and allows him micro-credit when he needs it. One of the best aspects of the savings group is the community emergency fund, which is funded by members' contributions and allows those who are ill to travel to the hospital and access treatment.

Thanks to these initiatives, Venancio can now afford to send his son to boarding school in Pemba. He says being able to give his son a good education is the biggest benefit of these projects for him.

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ILEP continues to focus on the stigma surrounding leprosy



FINANCIAL HIGHLIGHTS 2020

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

	2020	2019
Staff costs	183,859	341,602
Services from third parties	89,449	21,900
Rent, maintenance and insurance	8,209	20,977
Administrative expenses	14,663	25,127
Comms and IT expenses	12,217	26,469
Travel and meeting costs	21,560	95,819
Financial expenses and Taxes	4,121	4,090
Total Expenditure	CHF 334,078	CHF 535,984
Membership contributions	342,887	490,596
Reimbursements and other income	2,474	21,690
Total income	CHF 345,361	CHF 512,286
Financial result	CHF 11,283	CHF -23,698

In addition, ILEP Members contributed CHF 289,013 (2019; CHF 337,636) towards the operation of the Global Partnership for Zero Leprosy.

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

Damien Foundation Belgium

Deutsche Lepra- und Tuberkulosehilfe |
German Leprosy and TB Relief Association

effect:hope

FAIRMED

Fondation Raoul Follereau

Fontilles

Leprosy Relief Canada | Secours aux Lépreux

Lepra

NLR International

Sasakawa Health Foundation

The Leprosy Mission International





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