



until
No Leprosy Remains

Annual Report 2019

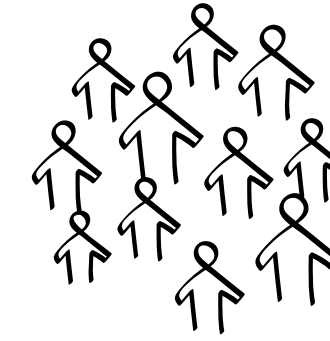
Working together to fight leprosy



Towards a world free of leprosy and its consequences

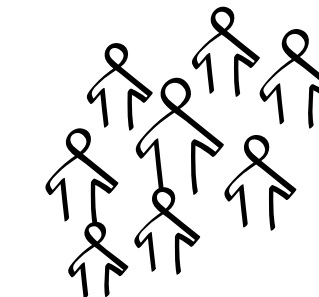
*number of new leprosy
patients detected worldwide

1985



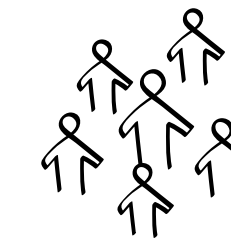
550,224*

1995



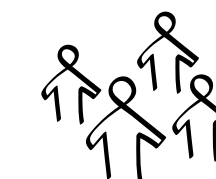
529,376*

2005



296,499*

2018



208,619*

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The year in review



Vision, mission, story



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Together we
make a
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Zero Transmission



Zero Disabilities



Zero Exclusion



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Financial Highlights
2019: income



Financial Highlights
2019: expenses



Other points of
interest



NLR Budget 2020



2019 in brief

until No Leprosy Remains

In 2019 the NLR Alliance developed three strategic programmes that best serve our mission: Zero Transmission, Zero Disability, and Zero Exclusion. NLR made important steps to sustain the future of these strategic programmes under local governance. Our teams in India, Indonesia and Nepal made great progress in developing and registering local NGOs. These organisations should not carry a brand like Netherlands Leprosy Relief. Therefore, from 2019 onwards NLR is used as our international brand. These three letters form the core of our mission: until No Leprosy Remains.

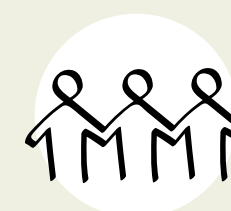
Our results

**39,149**

New leprosy patients detected

**6,352**

Health staff trained on leprosy

**42,798**

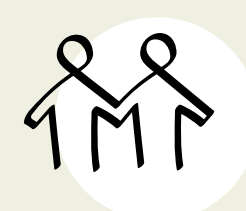
People who received information

**22,609**

Persons who received SDR-PEP

**8,478**

Persons affected by leprosy trained in self-care

**842**

Groups and organisations that NLR works with

Our highlights

PEP workshop

NLR organised an international workshop on Post-Exposure Prophylaxis (PEP) for leprosy together with the Global partnership for zero Leprosy and the Leprosy Research Initiative.

Ready4PEP project approved

NLR received funding to start an implementation project in Mozambique and Nigeria aiming to break the chain of leprosy transmission.

Signing transition agreements with NLR Nepal and NLR Indonesia

The NLR CEO and the chairs of the boards of NLR Nepal and NLR signed the Transition Agreements and NLR Alliance Membership Agreements. A truly historic moment!

Urban leprosy approach

NLR India and NLR Indonesia increased access to services and improved quality of services for persons affected by leprosy in urban areas.

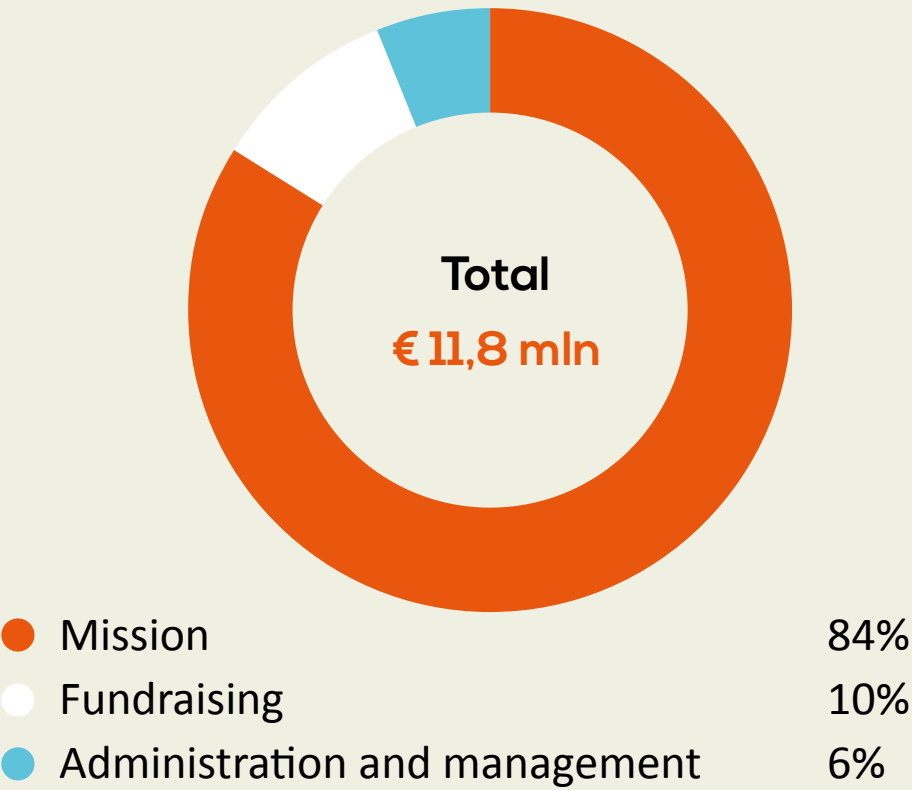
How did we spend our money in 2019?

In 2019, we received a total of € 8,3 million of income. We spend € 9,9 million on our objectives, which is 84% of our total expenditures. The continued support of our institutional and individual donors is vital as it enables us to diagnose, treat and cure persons affected by leprosy across three continents. Throughout the Netherlands, we received support from 43,116 donors and around 350 volunteers. NLR receives an annual contribution of € 1,350,000 from The Dutch Postcode Lottery and its participants. This is much appreciated, particularly as it is unearmarked income which we are free to allocate where and when it is most needed.

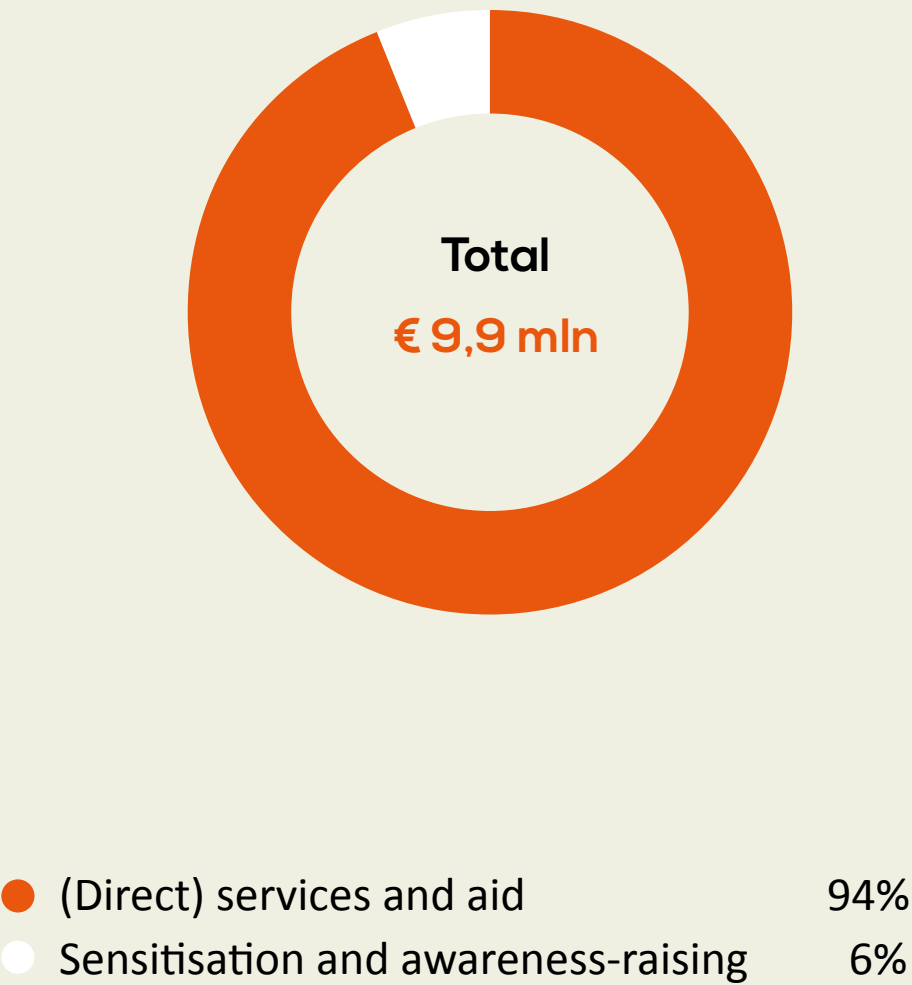
Other details concerning our income and expenses are shown in the Annual Accounts.

Annual accounts

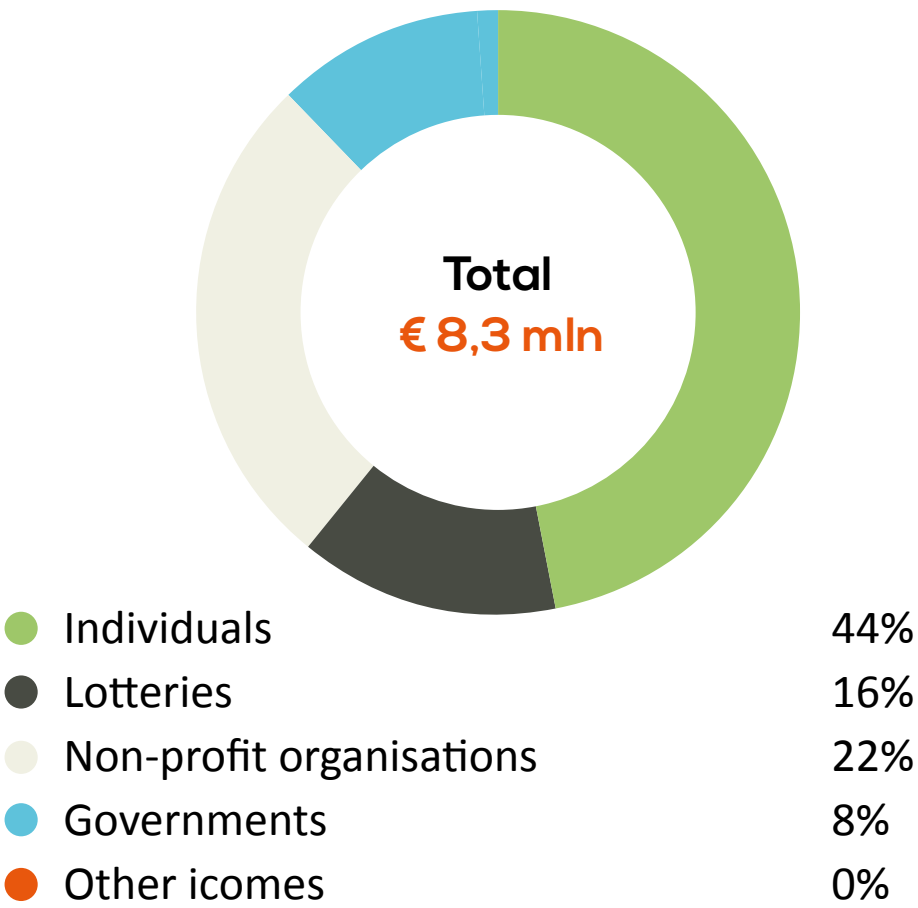
This is what we spent in 2019



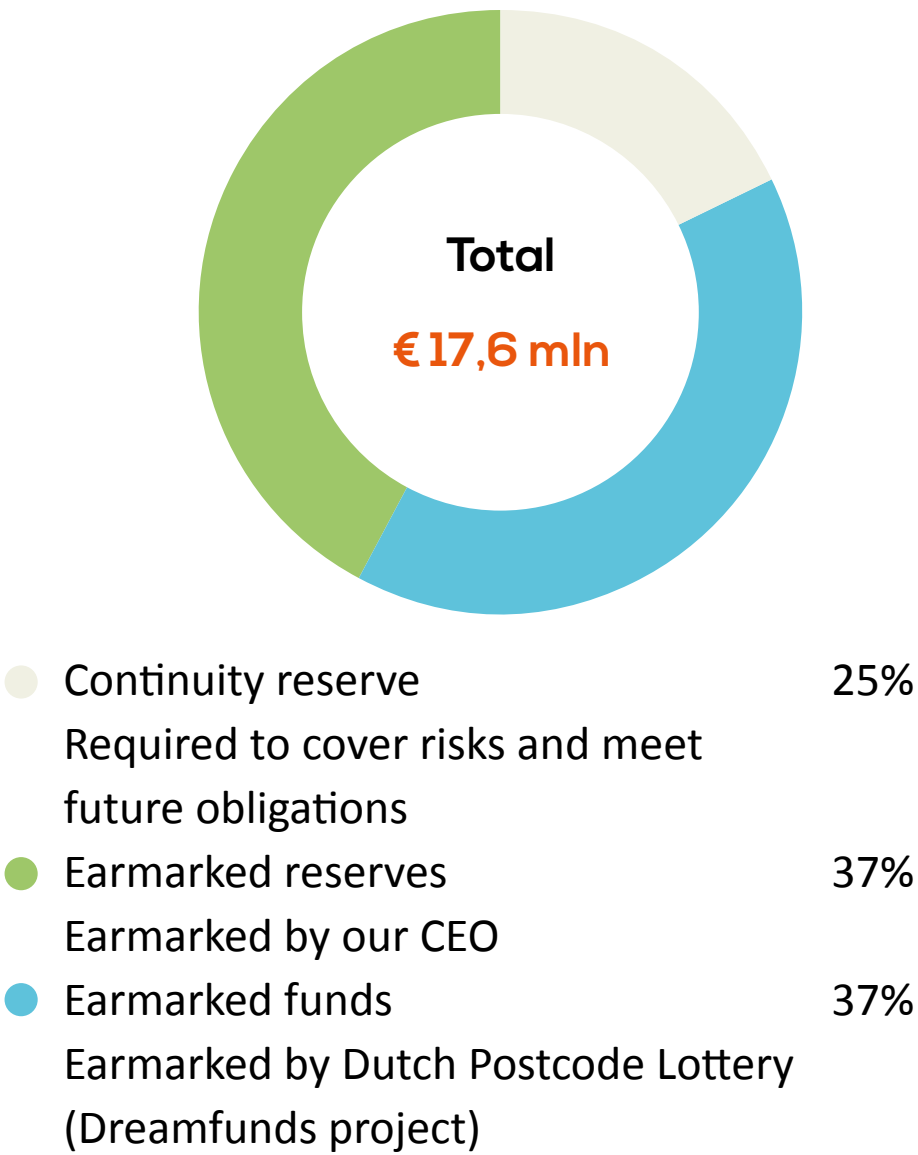
This is what we spent on our mission in 2019



This was our income in 2019



In support of our mission, these were our reserves and funds in 2019



SWOT Analysis

Our organisation

Strengths

- A track record of over fifty years in evidence-based programmes.
- Strong research capacity and close cooperation with research institutions in the Netherlands and our programme countries.
- Experience in the development and implementation of innovative approaches (e.g. SDR-PEP; SkinApp).

Weaknesses

- Limited number of staff relative to the scope of work.
- Growing dependency on external funding.
- Substantial part of senior technical capacity will soon retire.

Opportunities

- Fundraising potential for innovative approaches.
- Organisations in related fields show interest in NLR knowledge and best practices (e.g. the prevention of disabilities and stigma related to NTDs).
- Cooperation and partnerships with the Global Partnership for Zero Leprosy and the International Federation of Anti-Leprosy Associations (ILEP) open up opportunities for global and national roadmaps to zero leprosy, requiring strong NGO involvement and initiatives.

Threats

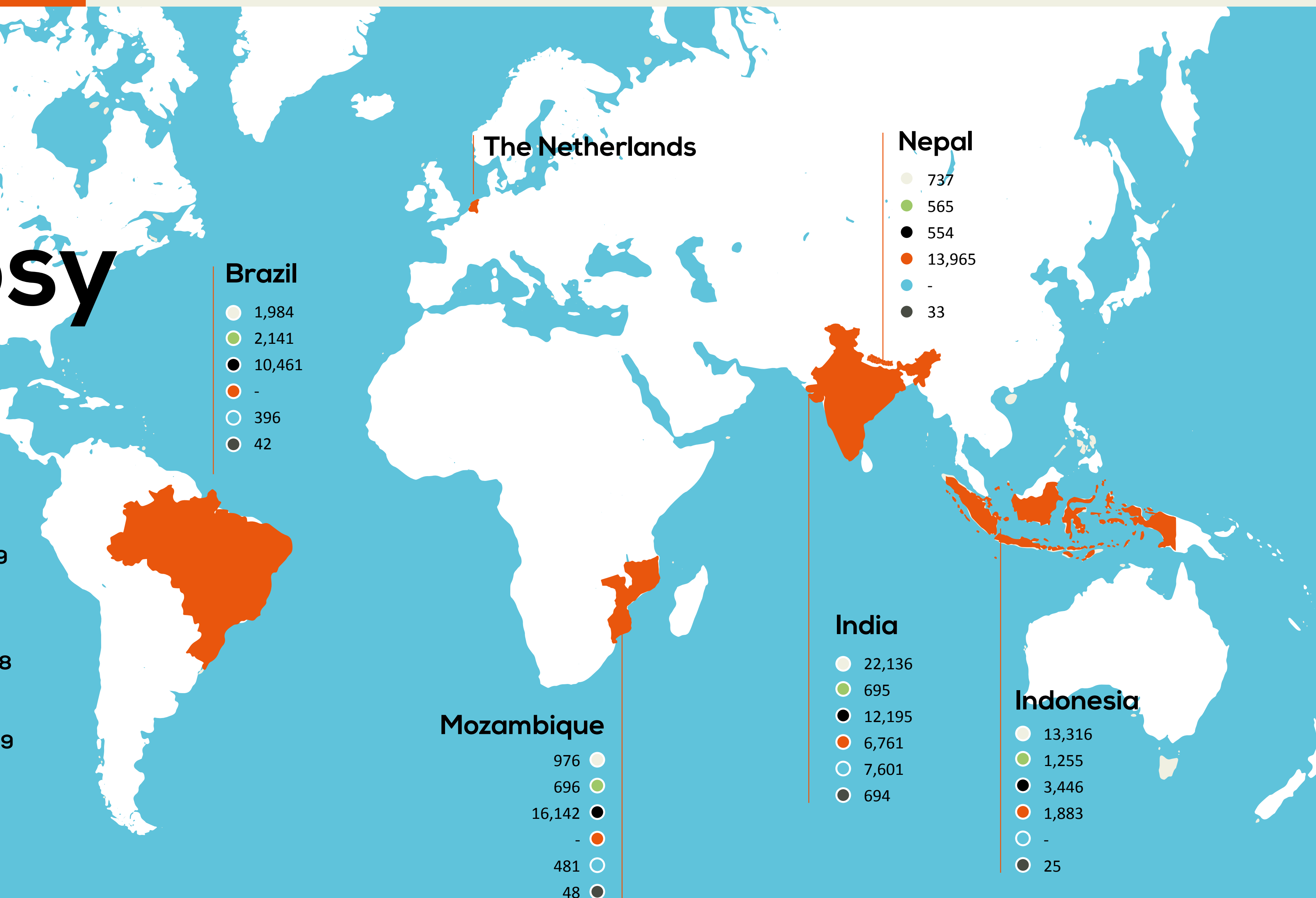
- Highly competitive fundraising market, both locally and institutionally.
- COVID-19 and restrictive measures by governments delay project implementation creating backlogs affecting our beneficiaries.
- Sharp decline in technical leprosy capacity worldwide.

until No Leprosy Remains

IN 2019

● New leprosy patients detected	39,149
● Health staff trained on leprosy	6,352
● People that received information on leprosy and/or disabilities due to leprosy	42,798
● Persons that received SDR through direct and indirect support of NLR	22,609
○ Persons affected by leprosy (with and without disabilities) trained in self-care	8,478
● Actors NLR is working with	842

Read about our indicators →



2019 in review

In 2019 NLR developed and expanded its operations as a family of mission-driven people. We connected with thousands of partners and stakeholders at local, national and international levels, who all share our dedication to see the end of leprosy. These include persons affected and their families, people at risk of developing the disease, volunteers and professionals who dedicated time and the best of their abilities to programmes and support functions within the NLR Alliance and our partners.

Decentralising our governance

In 2019 our teams in India, Indonesia and Nepal made great progress in developing and registering local NGOs: NLR India Foundation, NLR Indonesia and NLR Nepal. These registrations fall under the governance of local boards with the aim of securing the sustainability of our programmes, as we foresee our work will remain important and needed for many years ahead. We were delighted and encouraged that very competent and inspiring local volunteers took up the important responsibilities as board members of the new locally registered NGOs. Their Chairs convened in 2019 at the first meeting of the NLR Council of Chairs to discuss, amend and agree on the principles and procedures that will guide our continued collaborations in the NLR Alliance.



Under normal circumstances NLR is always keen to publish its annual report before the 1st of July. However, due to COVID-19 lockdowns financial audits in several offices could not be executed in time. We apologize to our donors for this unusually delayed Annual Report and Accounts 2019.

What's in a name?

As the new NGOs have the desire to continue their collaboration under one brand, we decided to redefine our international identity. Local NGOs can and should not carry a brand like *Netherlands Leprosy Relief*, which has served as an effective name for our Branch Offices. From 2019 onwards, NLR is used as our international brand. These three letters form the core of our mission: **until No Leprosy Remains**.

“Yes, we aim for the day that the world will celebrate Zero Leprosy, that wonderful day when NLR will close shop, mission accomplished!”

In 2019 we continued our active engagements in partnerships and various forms of collaboration. NLR participated in the further deployment of the Global Partnership for Zero Leprosy (GPZL), a growing and very unique all-stakeholder initiative to boost efforts towards covering the remaining research gaps and support the development of national partnerships driving their national Roadmaps to Zero Leprosy. NLR also actively participated in the International Federation of Anti-Leprosy Associations (ILEP). NLR staff contributed as President of the Board and the Members Assembly, and through membership of our Technical Commission. In many countries NLR Country Directors acted as ILEP coordinators, promoting alignment between the NGOs and with governmental public health programmes.

Pioneering in innovations

After introducing Post-Exposure Prophylaxis (PEP), a preventive treatment, in leprosy programmes in 2012, NLR has continued its leadership role in promoting and further improving PEP. NLR considers PEP as our number one priority and our best effort towards achieving Zero Leprosy.

At the International Leprosy Conference 2019, PEP was one of the topics discussed extensively and with great enthusiasm by many international stakeholders. Following on from this, in November we hosted a joint international PEP workshop in The Netherlands, together with the Global Partnership for Zero Leprosy (GPZL) and the Leprosy Research Initiative (LRI). Representatives of leprosy departments in Ministries of Health and their NGO partners exchanged experiences and challenges regarding the introduction of PEP in their leprosy programmes. Researchers met to share recent findings and discuss additional studies needed. Other participants reflected on the challenges of upscaling and rolling out PEP as an integrated part of their interventions in all endemic regions.

In 2019 NLR took important steps to sustain the future of our programmes under local governance. We also strengthened our focus on innovative contributions to break leprosy transmission and prevent the human suffering caused by leprosy. NLR will continue to do so, **until No Leprosy Remains!**



Bram van Ojik

Chair of the Supervisory Board



Jan van Berkel

Chief Executive Officer

Vision, Mission, Story

Leprosy still ruins millions of lives. It is a bacterial disease that can be treated and prevented. For centuries it was seen as a punishment, and in some cultures and communities it still is. Making a living, getting married, raising children and being valued by family and friends can be very difficult for a person affected by leprosy. Over the years, numerous medical and social breakthroughs have been achieved, but for those who are still affected, the mental, physical and socio-economic impact of leprosy is incredibly high.

Vision

A world free of leprosy and its consequences

This is the vision that drives our organisation – it inspires us to serve people at risk of infection and persons affected by leprosy around the world.

Mission

In pursuit of our vision, our mission is: **to prevent, detect and treat leprosy, and support health, ability and full inclusion in society for persons affected by leprosy.**

About NLR

NLR takes pride in enabling research and driving evidence-based innovation. We are directly engaged in supporting leprosy programmes in endemic regions in order to maximize their efficacy.

A recent major breakthrough for populations at risk of developing leprosy is a preventive treatment in the form of an antibiotic called SDR-PEP. It has proven to be effective against leprosy. SDR-PEP brings us closer to slowing down and eventually stopping the transmission of leprosy. We dream of the day when children no longer have to suffer like their parents and grandparents did. Together with international and local partners, we are working to make this ancient disease truly a thing of the past. This drives our ambition to continue **until No Leprosy Remains**.

Where we work

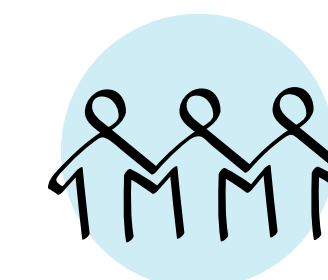
The NLR Alliance has offices in Brazil, Mozambique, Indonesia, India, Nepal and the Netherlands. In 2019 a worldwide total of **221 employees** were working together to aim for zero leprosy.

Stronger together: transitioning to the NLR Alliance

Over the last 50 years NLR has been one of the major change-makers towards a world without leprosy. We take pride in enabling research and driving evidence-based innovations. To better serve our mission, we are transforming NLR into an alliance of local NGOs.

In 2019 NLR Nepal and NLR Indonesia were the first members that have signed the Transition Agreement - a historic moment for NLR. They are the first members to enter a one and a half years transition period in which NLR will hand over full control of programmes, staff and funding to these local NGOs.

In addition, in 2019 NLR took the first major steps towards the formation of an alliance of NGOs with a shared vision and mission. NLR Nepal and NLR Indonesia were the first members to sign the NLR Alliance Membership Agreement. In India, the implementation of parts of the NLR programme was already managed under a locally registered NLR India Foundation before the start of 2019, but during that year a new board was appointed to govern this NGO. Discussions on the agreements between the NLR India Foundation and NLR continued until the end of 2019. We are confident that NLR India Foundation will join as a full member of the NLR Alliance in early 2020. We intend the full NLR Alliance to include also NHR Brasil and NLR Mozambique and expect to celebrate this moment in 2021.



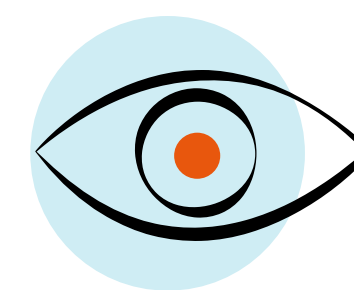
“In 2019, a worldwide total of 221 employees worked together to aim for zero leprosy.”

Sense of urgency for leprosy

People have suffered from leprosy and its consequences for thousands of years. Despite incredible developments in medicine, people in the poorest regions of our planet still suffer from this ancient disease. In the mid-1980s, when there were about 12 million leprosy patients globally, the World Health Organisation (WHO) introduced multidrug therapy, which led to a significant decrease in the number of patients receiving treatment. In the last ten years, the number of new leprosy patients detected annually has been almost stable, with around 210,000 new patients, including over 16,000 children, reported annually. Despite these numbers, the level of awareness in the Netherlands about leprosy remained very low in 2019. Many people look at it as a problem from the past, resulting in very little attention and priority given to leprosy (inter)nationally. Therefore, in 2019 we took steps to bring the urgency of leprosy to the attention of our current and potential individual donors and reached out to them through new channels to strengthen the structural commitment of their unearmarked donations. They are key to secure our ability to do research on, and introduce pilots of, new and improved methods and medication to prevent leprosy.

Research shows there may be a large number of persons with leprosy who remain undiagnosed and untreated. These undetected cases represent a major threat to leprosy control and contribute to a continuous risk of infection in communities. Moreover, a delay in timely diagnosis and treatment contributed to an estimated 3 million people who today live with disabilities due

to leprosy. In 2018 the WHO included SDR-PEP in the Guidelines for the Diagnosis, Treatment and Prevention of Leprosy. In 2019 NLR decided to further sharpen its focus on stopping the transmission of leprosy, with SDR-PEP as catalyst to achieve that goal.



“There may be a large number of persons with leprosy who remain undiagnosed and untreated.”

Complexity of our work

To successfully implement SDR-PEP in national programmes, many stakeholders with a variety of interests need to be involved and aligned to efficiently work together. In 2019 NLR actively worked with governments, non-governmental organisations, research institutions, Disabled People's Organisations (DPOs) and persons affected by leprosy.

More research is needed to fill knowledge gaps and make a strong case for embedding SDR-PEP in national leprosy programmes in endemic countries. As with any innovation in the medical field, the introduction

of SDR-PEP has met with some resistance. This also required NLR to advocate for the immense potential of SDR-PEP and to convince stakeholders that this is currently the most effective preventive treatment available that needs to be implemented in order to work towards stopping transmission. Simultaneously in 2019, with important support from The Dutch Postcode Lottery we continued to conduct research in finding the best enhanced preventive treatment. This study was met with a great deal of enthusiasm from various stakeholders, including those who expressed criticism of a preventive regimen with a single drug.

Risks and uncertainties

From our annual risk analysis, shortage of revenue continues to be the largest threat to the continuity of NLR's operations. However, 2019 brought more success in institutional fundraising to further expand the introduction of PEP in close cooperation with our country teams. Training will be continued to strengthen their ability to tap into more diverse and local income sources. The results of our Dutch individual fundraising have stabilized thanks to a growth in new, committed donors, but we are facing a decline in incidental donations.

Staff security is another point of concern. In several countries where NLR has operations, there is a high incidence rate of road traffic accidents. Strict security procedures for staff travel are continuously updated and revised. Fortunately, no serious accidents took place in 2019.

Our donors



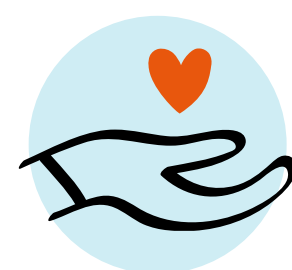
Together we make a difference

With the help of our individual and institutional donors, 2019 saw many persons affected by leprosy across three continents diagnosed, treated and cured. Moreover, they enabled us to continue our commitment to combat discrimination and promote inclusion for persons affected by leprosy. Our global efforts are only possible because of the generous and essential donations from our individual and institutional donors, and with the help, commitment and collaboration of ambassadors, volunteers, partners and other organisations. It is only by working together that we can truly make a difference and continue until No Leprosy Remains.

Individual donors

Individual donors are the heart of our organisation. At NLR we highly value our donors and aim to tailor our communication around them. We do this by adapting information materials to their wishes and needs. Moreover, we are transparent about our spending and are accountable to those who entrusted their resources to NLR.

In 2019 our individual donors donated a total of € 4,4 million. Legacies are considered as special gifts which amounted to a total of € 1,9 million for that year. We feel honoured that many donors trust us to spend their legacies for the benefit of persons affected by leprosy after they have passed away. We want to live up to that trust through targeted information about results and ground-breaking developments, but also by enabling persons affected by leprosy to share stories about what the support of donors in the Netherlands means to them.



“We feel honoured that many donors trust us to spend their legacies for the benefit of persons affected by leprosy.”



Institutional fundraising

A growing part of NLR's annual income comes from institutional sources, such as foundations, governments and multilateral organisations, which is crucial to reach our mission. Partners such as the Dutch Postcode Lottery, the European & Developing Countries Clinical Trials Partnership (EDTCP) and the Dutch Ministry of Foreign Affairs are crucial to reach our mission.

In 2019 we devoted a great deal of time and energy to the development of larger proposals in cooperation with other international NGOs, universities and networks. These remain pending with the institutional donors into the new year. This year we welcomed a number of new funding partners on board to our mission and we are pleased to have signed various new contracts with existing funding partners. From our biyearly donor survey we are gratified to note that our expertise, implementation and quality of reports are highly appreciated.

The Dutch Postcode Lottery

We have been a beneficiary of the Dutch Postcode Lottery since 1996, receiving an annual contribution in 2019 of € 1,350,000.

This is much appreciated, particularly as it is unearmarked income which we are free to allocate where and when it is most needed. The Dutch Postcode Lottery is therefore one of the most important partners of NLR. It also raises awareness of our fight against leprosy through their own communication channels, including national television during the broadcasting of Koffietijd (Coffee Time) on RTL4.

Dream Fund

In addition to this annual contribution, in 2017 we received € 9,375,000 from the Dutch Postcode Lottery 'Dream Fund' which helps to fund our five-year '**Stop the transmission of leprosy**' project. This project seeks to halt the transmission of leprosy with an enhanced preventive treatment in two districts in each of the three countries with the highest global leprosy burden: India, Brazil and Indonesia (together they account for 81% of all new leprosy patients). Within the project we target the closest contacts of persons affected by leprosy who were diagnosed over the last five years, with an enhanced dose of antibiotics. In addition, more distant contacts receive a single dose of SDR-PEP to reduce their risk of developing leprosy. For more information about this project please [see page 22](#).



EDCTP Interview



PEP4LEP is one of the new multi-country projects NLR started in 2018 with partners in Mozambique, Ethiopia and Tanzania, Germany and the Netherlands. This clinical research project is funded by the European & Developing Countries Clinical Trials Partnership (EDCTP) and the Leprosy Research Initiative (LRI). The EDCTP programme is supported by the European Union. Dr. Michelle Helinski, Project Officer at EDCTP, shares her thoughts about this joint project.

How does EDCTP's mission connect to NLR's mission?

“There is a good match between NLR's mission and EDCTP's mission on poverty-related infectious diseases. EDCTP aims to provide the evidence to guide informed decision-making on the introduction of new interventions. Moreover, EDCTP aims to build the capacity of African countries to plan, undertake and lead clinical studies of infections that are a national priority. Inclusion of vulnerable groups in the studies we fund is of special importance, like persons affected by leprosy in the PEP4LEP project. In 2017 EDCTP and the LRI created a partnership to increase the potential for improved North-South and interdisciplinary collaborative research on leprosy, which resulted in PEP4LEP.”

After one year, what are the highlights of the project?

“The project has had a very productive first year with many activities taking place in preparation for the inclusion of study participants. I particularly liked the interactive training materials developed to assist local health workers in the identification of a large number of skin diseases.”

What are your hopes for the collaboration with NLR and PEP4LEP in 2020?

“I am excited to see the project advance towards the inclusion of study participants and I look forward to hearing about this progress in 2020.”

For more information about this project please [see page 22](#).



Fundraising & Communications

Doing is believing

Our long-term strategy is focused on donor-centred fundraising. We want to demonstrate this ambition in everything we implement for our current donors but also in our information for new donors. A good start has been made with this in recent years, but we realise that we have to deliver on this promise every day.

Personal contact

Our service desk for individual donors is ready to answer questions personally and resolve complaints as well as possible. If desired, a relationship manager visits the individual donor's home to discuss the possibility of donating through legacies. Individual donor meetings allow for personal contact and for sharing more background information about our projects. In 2019 a meeting was held in Museum Speelklok in Utrecht for donors who supported a special project on leprosy control in Indonesia. The meeting was greatly appreciated by the donors who participated, captured in this quote from one attendee: "Information was explained clearly and we were very warmly received. It made us realise that with the help of our donations, leprosy can be beaten. In one word: great organisation!"

Increase loyalty and recruit new private donors

The number of active individual donors showed a decrease of 3.9% from 44,862 (2018) to 43,116 (2019), mainly due to retirement, old age or demise. We depend on individual donors to continue our work, so in 2019 we invested in recruiting donors through new channels like door-to-door and online, and increasing the loyalty of existing donors through telemarketing. Individual fundraising is under pressure due to various external factors. The Dutch government is drafting various measures and laws that hinder fundraising by NGOs like NLR. Together with branch organisations Goede Doelen Nederland, NLR objected against plans to make it obligatory for organisations to publish the name and place of residence of generous individual donors, reduce the tax benefit for recurrent donations, and implement stricter legislation on telemarketing.

“We were very warmly received. It made us realise that with the help of our donations, leprosy can be beaten. In one word: great organisation!”





Other ways of fundraising

Recruiting new individual donors by regular direct mail yields insufficient results. In the second quarter of 2019 we carried out a very successful test to recruit door-to-door donors. As a result, almost 2,000 structural individual donors were recruited in 2019 via door-to-door. This higher number of structural individual donors provides NLR more certainty about the amounts of donations expected in coming years. The total amount of structural donors by the end of 2019 was 10,480 (increase of 16%). This success led to the decision to continue this way of personal recruiting in 2020. The number of incidental donations decreased by 3,255 (down 9% from 2018).

Furthermore, in telemarketing we changed our focus from recruiting single donations to structural individual donors. As a result, we raised the number of structural donors by 1,100. We also asked loyal donors to increase the amount of their gifts, resulting in an upgrade in the annual amount donated by 400 individual donors. For new individual donors we have created a welcome programme of brochures, e-mail and thank you phone calls.

In 2019 we entered into a partnership with the Jan Kruis Museum in Orvelte, which opened in May 2019. During his life Jan Kruis was a committed ambassador of NLR. An exhibition space in the museum is dedicated to Jan's creative work for NLR and half of the proceeds from merchandising go to NLR.

Listening and Acting

We received a total of 55 complaints in 2019. The main concerns were «too much mail», «extra gift request not desired» and «door-to-door recruitment undesirable». All complaints were promptly dealt with and, depending on the nature of a complaint, either explained or investigated. Heartfelt apologies were usually sufficient to undo the irritation expressed. Given the more active individual donor approach, we learned a lot from these complaints. In 2019 we made a start with setting up a new Customer Relationship Management system in order to better capture the needs of our individual donors and to customize our communication and fundraising activities to their expectations. We regularly post the most frequently asked questions and answers on the website to meet initial information needs. In 2019 we also carried out a donor survey, the results of which will be known at the beginning of 2020.

Individual donors, ambassadors and volunteers and their motives for supporting NLR



“A leprosy-free world is possible.
If I can contribute, I will gladly do so.”

Wil Ottens, individual donor



“It is important to me that a charity
is neutral with regards to religion
and that the people who carry it
out are persistent.”

Sipke van Belle, individual donor



“I am happy that I can mean a lot to
persons affected by leprosy”

Peter Euser, Ambassador, volunteer campaign
organiser over many years



“As the Dutch Mayors' football team, we have
been raising sponsorships by playing football
for NLR for more than 30 years. Councillors also
joined in mid-2019. Together, we can continue our
important contribution in the fight against leprosy.”

Jos Heijmans, Chairman of the Nederlands Burgemeesters
& Wethouders Elftal (NBE)



“We are a close-knit group of volunteers. It
gives us a good feeling that we help persons
affected by leprosy with our work.”

Alie Kattenbeld, volunteer at the Leprosy shop in
Deventer where 50 people have volunteered their
services for over 40 years



“I know for whom I am doing it.
It is always exciting how much money we
have collected together. After all, every
euro counts!”

Marianne Groeneveld, volunteer, organiser of the
annual collection week in Noord-Brabant since 2000



“My father has supported NLR as an
ambassador for years to fight leprosy.
It is wonderful that we can continue his
work with the Jan Kruis Museum.”

Leontine with her mother Els Kruis during the
opening of the Jan Kruis Museum



“I was very young when I first heard
about leprosy through the stories about
Father Damien. I'll never forget that. That
is why I am committed to NLR.”

Huub Stapel, celebrated actor and NLR Ambassador

Sharing is caring

It is essential to build a bridge between those who support our fight against leprosy and the persons affected by leprosy. Leprosy is an issue far from home for many Dutch people and is seen as a disease of the past. By making clear that large numbers of people still have to deal with the devastating consequences of the disease every year and that a world without leprosy is a concrete and realistic goal, we re-frame leprosy as an urgent issue. In 2019 storytelling was an important way to deliver this message. By sharing emotional and personal stories, like the story of Ansubai, we gave an abstract far away concept like leprosy a recognisable face. We use storytelling through online videos, TV (Socutera) and digital newsletters. In addition, our donor magazine «De Klepper» appears every quarter and we send out a newsletter, which is the main channel of communication with our current individual donors. During World Leprosy Day 2019 we drew worldwide attention to leprosy control, with a special focus on stigma and discrimination.











Online channels

NLR can still grow in the use of online channels for fundraising. Important first steps have been taken in 2019, to be further continued in 2020 and beyond. For the coming years it is important to use online channels more effectively. The renewed websites www.leprastichting.nl and www.nlrinternational.org were launched in January 2019 and throughout the year we increased the use of Facebook and updated the website more frequently, resulting in more followers. The choice of a continuous campaign (regular visibility) and the use of a mainly online campaign in autumn 2019 also generated more followers and more visitors (see table).

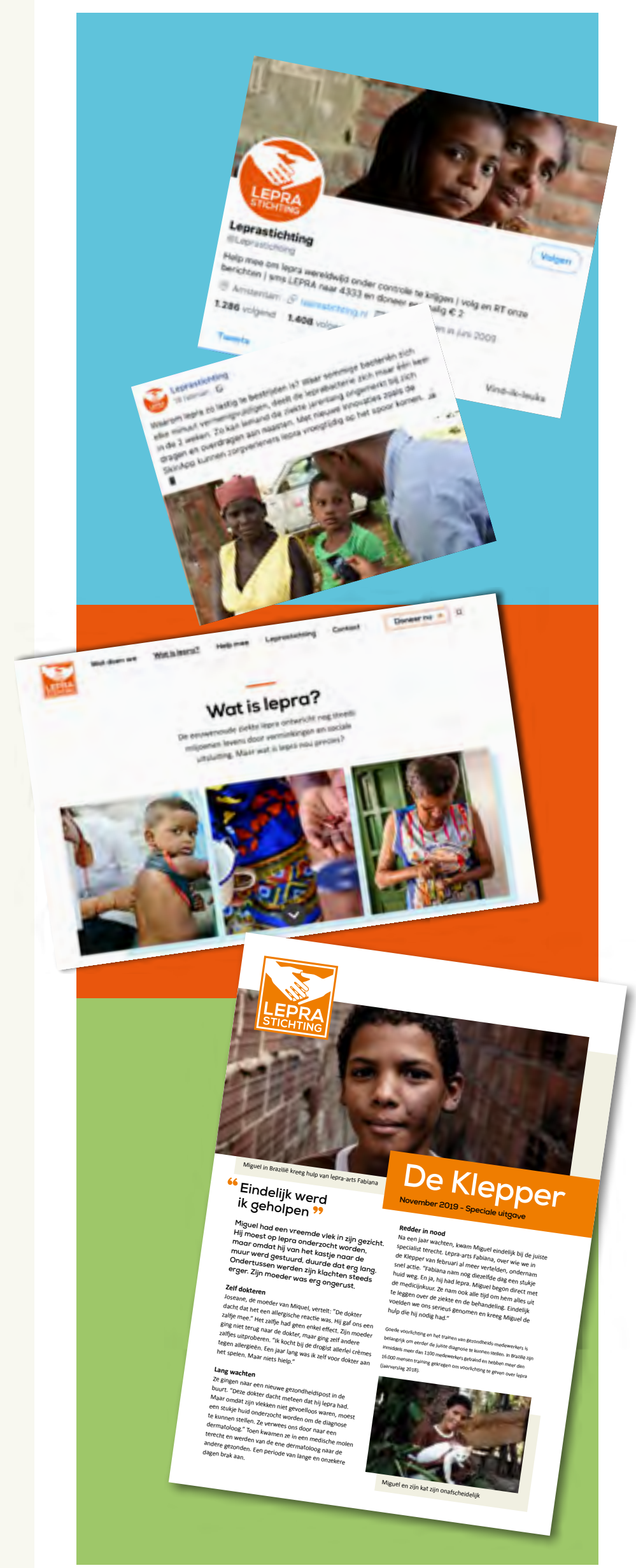
Campaign

The communications campaign during autumn 2019 in The Netherlands was primarily online. An interactive game to trace persons affected by leprosy was central to the campaign flow. The primary emphasis was on building brand awareness, while increasing donations served as a secondary goal. The campaign, included marketing PR and focused on presenting results of an online survey with the theme "The Unfamiliarity and Misconceptions about Leprosy in the Netherlands."

Leprastichting: increase online channels in 2019

	2018		2019
 Followers on Facebook	1,850		1,958
 Followers on Twitter	1,371		1,408
 Unique website visitors	40,147		81,653
 Youtube reach, views and viewing time	42.200 5.546 156,9 hrs		71.900 30.795 204,7 hrs
 Newsletter subscribers	March 4.106		Dec 4.556

Results Leprastichting/Dutch website and social media



Brand awareness

To differentiate from other charitable organisations, brand awareness is crucial to NLR. More than ever we need to demonstrate the uniqueness, effectiveness and relevance of our cause. In June 2018 an external consultant conducted a baseline study for the brand Leprastichting that laid the foundation for a new brand strategy in 2019. To evaluate the impact of our new approach, the study will be repeated bi-annually.

Brand NLR

In 2016 we began to transform our Country Offices and International Office in the Netherlands into an Alliance of locally registered NGOs. To ensure the maintenance of the brand awareness of Leprastichting and NLR, uniformity in brand images is essential. To this end, in 2019 we slightly adjusted our corporate identity guidelines and strengthened our international tagline: until No Leprosy Remains. These adjustments are incorporated into a user-friendly brand manual to create synergy in all communications of the NLR Alliance, both nationally and internationally.

Results

The interactive game of the autumn campaign contributed to a small increase in brand awareness. Together with increased online media coverage throughout the year, the campaign also resulted in a significant increase in web visits and online followers. The marketing and communication efforts resulted in free publicity with an estimated media value of more than € 120,000 and audience reach of 1.8 million. Social media videos designed to generate traffic to the website scored above the market average, but unfortunately the game did not meet its targets. Web visitors did not play the game to the end, so the conversion to donations was disappointing.

Learnings

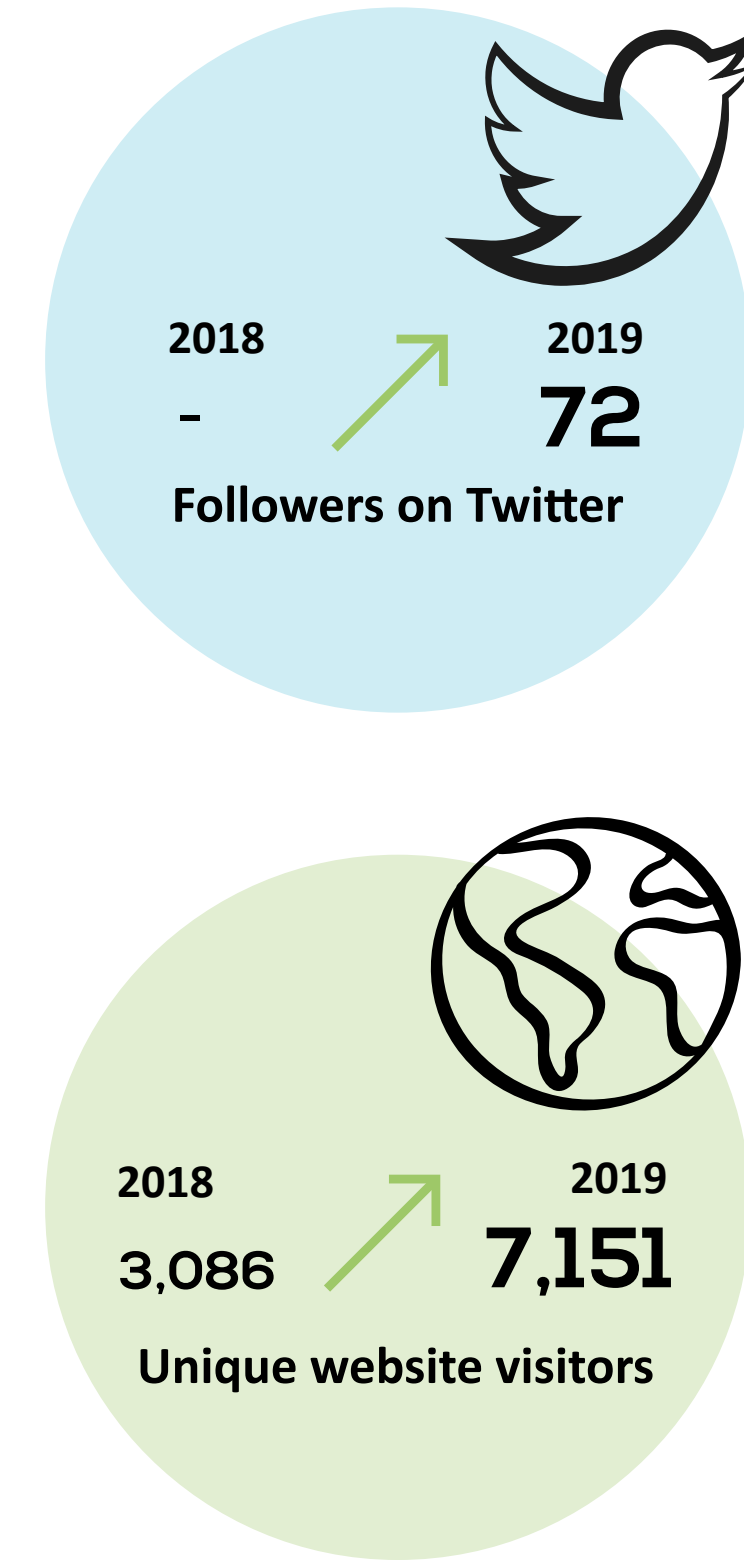
We will adjust the next campaign using the insights gained. The objectives of raising both brand awareness in combination with an ambitious donation target does not seem realistic. Regarding new individual donors, more media coverage throughout the year is essential to achieve more top-of-mind-awareness with our target group.

Leprastichting: slight increase of brand awareness

	2017		2019
Brand awareness (helped)	44%	↗	46%
Brand awareness (spontaneous)	0,4%	↗	1,8%
Brand strength	97	↗	100
Brand strength score position (international Aid NGO brands)	11	→	11

Despite a slight increase, brand awareness is very low. The aim is to increase this in the coming years by being more visible throughout the whole year.

Number of followers on social media on 31 December 2019 NLR



Results include NLR international website and social media

A photograph of a person with leprosy, showing skin lesions, working with a traditional tool on a piece of wood. The person is wearing a light-colored skirt and is barefoot. The background is dark and textured.

Zero Transmission Zero Disabilities Zero Exclusion

Short Introduction

In 2019 the NLR Alliance developed three strategic programmes: Zero Transmission, Zero Disability, and Zero Exclusion. The Zero Transmission programme aims to reduce the transmission of the leprosy bacteria. The Zero Disability programme aims to prevent persons affected by leprosy from developing new disabilities during or after treatment. In our Zero Exclusion programme we aim to improve lives of persons with disabilities due to leprosy by enabling access to services and participation in community activities. Together they contribute to our vision of a world without leprosy and its consequences. In all aspects of their lives, persons affected by leprosy are confronted with discrimination and stigma, fuelling a vicious circle of negative consequences: social exclusion, increased mental problems, increased economic vulnerability. We aim to embed interventions that focus on reducing stigma and discrimination in each Zero-programme.

Zero Transmission



NLR's programme on Zero Transmission of leprosy combines years of organisational experience in the field of leprosy control with promising innovations that help to prevent leprosy and diagnose and treat patients as early as possible.

There is a great deal of momentum to work towards Zero Transmission. Not only because ILEP's strategy and the WHO's Global Leprosy Strategy also formulated Zero Transmission as one of its goals, but also because new scientific findings, such as preventive medication, have brought this goal closer in sight. In 2018 the Global Partnership for Zero Leprosy (GPZL) was formed. NLR is an active member of this wide group of stakeholders that are highly motivated and committed to end leprosy. Governments are clearly demonstrating their commitment through involvement in several multi-country NLR coordinated projects, such as the Stop the Transmission of Leprosy! Project, PEP4LEP and Ready4PEP. All projects use innovative approaches to work towards Zero Transmission.

Our Focus

In collaboration with our partners in countries, NLR conducts research and implementation projects with innovative methods to improve leprosy control. Once these methods are proven to be effective in pilot areas, NLR aims to establish their operationalization and adoption and scaling-up to other areas and to other countries contributing the health system strengthening.

Our Actions

One of the important new possibilities in leprosy control is preventive medication in the form of single dose rifampicin (SDR-PEP). SDR-PEP reduces the risk of developing leprosy by 60% when given to contacts of leprosy patients. The LPEP Programme (2014-2018) has shown that, first, it is feasible to integrate SDR-PEP distribution in routine leprosy control, second, it is very well received by both patients and their contacts, and third, it strengthens health services because of the increased training and motivation of health staff involved. In 2019 NLR continued its research in the Stop the Transmission of Leprosy! Project on an enhanced preventive regimen, which is expected to have an even stronger effect: a risk reduction of 80-90%. Other research (PEP4LEP) focusses in different approaches to implement SDR-PEP in the most practical and cost-effective way.

A good level of awareness of early symptoms of leprosy in the community, together with knowledgeable health staff, are crucial to safeguard timely diagnosis and prompt treatment, which ensures that patients can no longer transmit leprosy bacteria. The Leprosy Friendly Village approach, developed by NLR Indonesia and implemented in North Minahasa District North Sulawesi Province in Indonesia, demonstrates how intensive health education involving key community representatives helps to improve knowledge and attitudes towards those affected by leprosy, contributing to early case identification and a reduction in the number of new leprosy patients. As of 2019 the success of this approach has inspired other villages to adopt it as part of their routine leprosy control programmes.

Zero Transmission

Flagship projects

Stop the Transmission of Leprosy!



The Stop the Transmission of Leprosy! Project financed by the Dutch Postcode Lottery's Dream Fund, received renewed ethical clearance in Brazil, India and Indonesia by the end of 2019. A mandatory change in the enhanced PEP regimen, called PEP++, occurred early in the year along with the decision not to use a serological screening test. These changes required protocol amendments to be submitted for approval in all three countries during the year. We now look forward to the full clinical trial moving ahead in early 2020.

While awaiting approval the three national teams finalised many preparatory stages in 2019:

- Mapping of new leprosy patients from 2014 to 2018 was completed in all countries leading to the development of detailed cluster maps. These maps allow the research teams to visualise the areas of highest risk for leprosy transmission and target them in mass administration PEP campaigns in 2020.
- Each country completed its leprosy perception study and produced tailor-made community education and behaviour change materials to reduce community discrimination and increase study acceptability. These materials will undergo final testing and full roll-out before the clinical trial begins.
- In the second half of the year a digital data management platform was developed that will allow all research data to be quickly uploaded from tablets in the field for national consolidation and international analysis.

PEP4LEP



There is limited experience with implementation methods for SDR-PEP. PEP4LEP is a research project looking at two different SDR-PEP implementation methodologies, comparing the effectiveness and feasibility of a skin camp intervention to a health centre-based intervention in Mozambique, Ethiopia and Tanzania. Participants in the PEP4LEP study are screened for leprosy and other skin diseases. This dermatological screening process is a WHO-supported method to detect neglected tropical diseases such as leprosy. NLR's SkinApp will be used as a tool which supports community health workers to diagnose and treat skin diseases. PEP4LEP started in October 2018 and by 2019 we had achieved some important milestones:

- Obtained ethical approval for the PEP4LEP research project in Tanzania and Mozambique.
- Hired four PhD students for the PEP4LEP project, three of whom are from sub-Saharan Africa.
- Trained health workers in the PEP4LEP project.
- Started to include the first PEP4LEP study participants in Tanzania and handing out the first SDR-PEP tablets.
- Presented PEP4LEP during the Spring meeting of the Leprosy Research Initiative and the International Leprosy Congress.
- Developed two games (NTD Skin Games), to support health workers in learning about skin diseases like leprosy, that were presented at the 2019 COR-NTD Meeting.

Zero Transmission

Flagship projects

SkinApp

In collaboration with Erasmus University Medical Center, NLR has developed the SkinApp, which aims to support peripheral health workers to recognize the early signs and symptoms of common skin diseases, including skin neglected tropical diseases (NTDs) and skin manifestations of HIV/AIDS. By enabling timely diagnosis and treatment of skin diseases, especially NTDs that manifest with skin lesions like leprosy, the SkinApp contributes to proper diagnosis and the prevention of disabilities as well as psychological and socio-economic problems. Skin diseases are among the most common of all medical conditions and skin examination offers an opportunity to screen people and to identify multiple conditions at the earliest stage possible in a single consult.

In 2019 the SkinApp was field tested in Ethiopia, Mozambique and Tanzania as part of the PEP4LEP project ([see page 21](#)), while cooperation with national dermatological federations in Brazil and Indonesia were initiated to start the development of country specific versions of the SkinApp. The SkinApp won the Apps Award at the ISNTD Festival 2019 and was well received at the WHO Buruli Ulcer meeting, the International Leprosy Congress 2019, the WHO meeting on mHealth Tools and at the IncoNTD meeting on NTDs in Africa.



Zero Transmission



From the field

“Informing the population may help to fight prejudice.”

Arlindo Santos

Story from Brasil

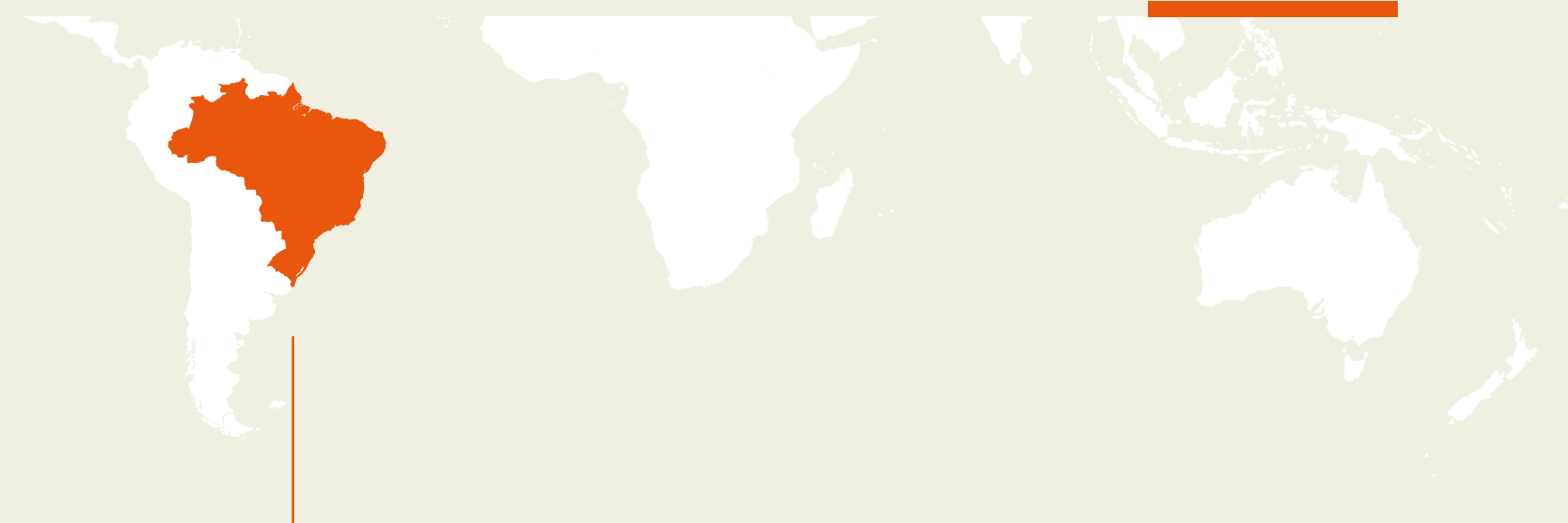
Arlindo Santos had lived for decades with a skin lesion on his chest. He said that the only strange fact about his mark was that the area seemed to redden whenever he entered a pool. It was not enough to make him think he had a disease. He wanted to get a tattoo on top of the mark, but his tattoo artist advised him to find out what the skin lesion was before tattooing on top of it. Arlindo eventually discovered he had leprosy.

Arlindo went to **ten different health professionals** until he had the correct diagnosis. He underwent a six month course of treatment without revealing his diagnosis to friends, family members or co-workers. *“It was a decision of mine. I wanted to have a fast cure and get rid of it without transmitting it to them”.*

He feels more comfortable to relate his experience now and he participates on a community radio station where he talks about leprosy. Arlindo says, *“Informing the population may help to fight prejudice. Media have the power to play a great role in this fight. We*

need campaigns about leprosy, just like we have about drugs, about drinking and driving or about the importance of vaccines”.

In 2019 Arlindo was approached by the Brazilian Stop the Transmission of Leprosy! Project team. *“Arlindo impressed our team with his resilience after a late diagnosis, after experiencing stigma. We identified him as a local leader for the way he was empowered to discuss his perceptions about leprosy. As a person affected, he feels that he can help disseminating information for many people in his community, and this is very important for us in the programme territories”*, says Nágila Lima, supervisor of field activities in Fortaleza.



Zero Transmission



From the field

“I thank NLR India for making people aware about leprosy.”

Pradeep Kumar

Story from India

Farmer Pradeep Kumar lives in Lalpur Baijani, a small village in Fatehpur-district, with his wife's parents and two children.

One day Pradeep noticed small patches on his skin which were numb to the touch. He put them down to changes in the weather and thought they would go away on their own. A few days later, under the Leprosy Case Detection Campaign, a health worker visited Pradeep's house. During the screening of the family members, Pradeep was also screened for signs and symptoms of leprosy. As the patches on Pradeep's body were numb, which is a sign of leprosy, he was referred to a hospital.

Pradeep visited the nearby health facility for further testing, where he was diagnosed with leprosy and put on a 12 month course of treatment with multidrug therapy.

Though Pradeep started taking the treatment he did not reveal the fact he had leprosy to anybody in his family because of his own negative feelings towards the disease. When he did eventually tell his family

members, they became scared and asked him not to discuss it with anybody outside the household.

After a few days a survey team of the Stop the Transmission of Leprosy! Project of NLR India went to visit the village. Pradeep was afraid everyone would know about his disease and people in the village would stay away from him.

The survey team met Pradeep and tried to remove his apprehension about leprosy by telling him that once he completes the course of MDT treatment he will be cured. He was also told that the disease is caused by bacteria and is not a result of a curse or punishment from God. To support this the team showed him information materials developed by NLR India. By looking through and understanding the information materials, Pradeep's apprehensions disappeared.

Later Pradeep took part in rallies organised to generate awareness about leprosy. He said, “*I thank NLR India for making people aware about leprosy.*”



Zero Transmission



From the field

“With the SkinApp, I am able to diagnose correctly and prescribe the correct medication.”

Milton Jose Antao

Story from Mozambique

Milton Jose Antao (27) works as a General Medical Technician. He is married and lives with his wife in Namanda Village, in the District of Ile in Zambézia. Milton uses the SkinApp to confirm new leprosy patients at Ile District Hospital in Zambézia Province.

“I came to know about the SkinApp in a training organised by an NLR Project Officer and the Provincial Leprosy supervisor in 2019. They installed the app on my smart phone. Before the SkinApp installation, my work was quite challenging. I had limitations in diagnosing skin diseases. This was contributing negatively to my ability to provide correct treatment to the patients.”

Milton acknowledges the SkinApp has increased his ability to diagnose skin diseases, thus adding value to his efforts to treat or refer patients. *“With the SkinApp, I am able to diagnose correctly and prescribe the correct medication. The training on the SkinApp helped a lot to improve my work as it also helps me in the consultation that goes beyond my capacity and gives me immediate response concerning leprosy patients”,* said Milton.



Zero Disabilities



Our goal with the Zero Disabilities programme is to stop persons affected by leprosy developing new disabilities during or after treatment when they are cured. Lifelong monitoring is required to prevent disabilities and the worsening of existing disabilities. Unfortunately, this aspect of leprosy after treatment receives much less attention from public health services and government health policies. Treatment of painful reactions that patients may experience after being treated with multidrug therapy is another area for consideration. It is important to monitor eye and nerve functions and apply wound care during and after release from treatment. Lack of monitoring can have severe consequences for those affected by leprosy who are at risk of developing further disability.

Important Aspects of Our Work

We think it is important that persons affected by leprosy learn to practise self-care, report complications, and demand for assistive devices or reconstructive surgery when they need it. They need to be treated with respect and without stigma, so that they do not feel afraid to ask health workers or staff of primary health centres (PHCs) for support. To stimulate persons affected by leprosy to do so, community health workers need to take up their role in monitoring on wound care, disability prevention and leprosy reactions. They can motivate patients to visit a primary health centre in case of complications and promote regular self-care. In turn, these health centres need to train both community health workers and persons affected by leprosy so that they can carry out these activities. With up-to-date knowledge, PHCs will be able to address disability prevention and complications. Where relevant, we support health

centres to apply combined approaches with other diseases in the prevention of disabilities, especially neglected tropical diseases such as lymphatic filariasis. The role of the national governments is to adopt and promote effective policies for the prevention of disabilities and provide assistive devices through these centres. International organisations such as WHO, ILEP and the NTD NGO Network (NNN) are important platforms in propagating these policies.

What We Do

To achieve this, we pilot new approaches for the prevention of disabilities and we support the government to scale-up these approaches when they have proven successful.. We strengthen the capacity of health workers in the prevention of disabilities through training of trainers. We lobby national and local authorities to implement policies, manage data and to allocate funds for the prevention of disabilities. We support the development of guidelines and tools, knowledge sharing and learning through national and international platforms so that organisations such as the WHO and ministries of health will adopt the good practices that we and others have developed.

Zero Disabilities



Flagship Projects

Mozambique: rehabilitation and prevention of disabilities



In 2019 NLR Mozambique supported prevention of disabilities and rehabilitation in various ways.

Via the PRODISA and DAP-Konzo projects, community health workers were trained in how to mobilize communities for the prevention of disabilities. In this approach communities are stimulated to participate in activities for early detection and treatment of diseases, and to reduce the impact of impairments by practicing self-care for wounds and community-based rehabilitation.

At village level, there is a huge shortage of physical therapists. Training of community volunteers in providing direct assistance to patients reduces this lack to a large extent. The training is supported by community-based rehabilitation centres built by NLR to reduce travelling distance to the health units for physical therapy. This is particularly relevant because persons with disabilities often face mobility challenges. In Nampula, the Morbidity Management, Disability and Prevention (MMDP) project has made an inventory of health units and carried out training of trainers and others in prevention of disabilities.

In Mozambique around 16,000 people have received information about disabilities due to leprosy, 696 health staff were trained about leprosy, and 481 persons affected by leprosy were trained in self-care.

India: a combined approach to the prevention of disabilities



NLR India uses a combined self-care approach to address prevention and management of disability due to leprosy and lymphatic filariasis. Teaching self-care to persons affected by these diseases enhances safe mobility and increases their ability to perform daily activities.

In 2019 NLR India implemented a project to improve the health of those affected by leprosy and lymphatic filariasis in six districts in Bihar and Uttar Pradesh, districts with the highest incidence of these diseases in the country. During the project, 1,643 persons affected by lymphatic filariasis and leprosy were trained in self-care. The project has capacitated 1,026 general health care staff of primary health centres in nerve function assessment, identification of entry points, swelling measurement to prevent disability and the implementation of disability management through self-care. A total of 104 persons affected by lymphoedema and leprosy have been identified for surgeries or re-constructive surgeries in two intervention states. Severe heat affected the project areas during the summer, resulting in a shortage of water for self-care. Nevertheless, the project managed to achieve the numbers mentioned above, and at the same time, to train community leaders to establish a network of trainers in self-care. These successes will be strengthened further in 2020.

Zero Disabilities



From the field

“I am thankful to NLR India for providing me a new life and now I am living a dignified life.”

Anjana Devi

Story from India

Anjana Devi suffered a great deal due to leprosy and faced discrimination from society. Her feet were numb, leading to disability. She consulted doctors in the village but did not receive a satisfactory solution for her ailments. After joining a self-help group supported by NLR India, Anjana was motivated to go to the hospital for treatment. She was closely supervised by the NLR India team while she completed her course of medicine and she received a Grade-2 disability certificate linked to the Bihar Shatabdi Leprosy Welfare Scheme which pays her pension each month.

In the past, Anjana was trained to make incense sticks, but due to lack of money she was unable to move forward. She took a loan from the self-help group, but because of her physical disabilities she was unable to

fix the necessary materials by hand in order to make incense sticks. She was therefore not able to make money out of her business, which led to frustration and disappointment for Anjana.

Then she approached NLR India who provided her with the financial support she needed for her business. With this loan she bought a machine for making incense sticks at home, enabling her to repay her loan. Anjana is now more empowered and has developed stronger self-esteem. People around Anjana are also learning from her how to make incense sticks and are eager to work with her.

Anjana Devi says, “I am thankful to NLR India for providing me a new life and now I am living a dignified life. Please help more people like me”.



Zero Disabilities



From the field

“I could not believe that the group would be so supportive of people like me.”

Anifa Nawepa

Story from Mozambique

Anifa Nawepa (59) is a widow with two older sons. She lives in the village of Sanhote, in Monapo District in Nampula. Anifa is an active member of a self-help group. She shares her story.

“I didn’t know what I had. I found out I had leprosy in 2014 when I was invited by the community volunteer, Mr. Chico to participate in an information meeting held in my village. After the session, Mr. Chico called me to join other participants who were affected patients because he noticed I had some deformities. I am a person with physical disabilities. Parts of my hands and feet have been amputated, and I have claw hands due to leprosy. The appearance of my body was not pleasant. I had stains that look like I am burned. In my neighbourhood many people including my family members laughed at me and despised me because I had disabilities. My face is totally changed because of leprosy and I have patches almost everywhere on my skin. The nurse did all the examinations and he said I had leprosy. He immediately gave me medication and explained how to proceed. I followed all the rules and after one year of taking drugs, the nurse informed that I was cured, and I did not need to take more medicine.

In 2018 the self-help group of which I am a member, received training in small business management. I participated in the training and asked for a loan for a business to acquire and re-sell cell phone recharge cards. I am very happy with my business. I saved my profits for 6 months. After starting a savings box I noticed that I was able to save some money. I could not believe that the group would be so supportive of people like me. This business helps me a lot and I thank you from all of my heart.

Members report improvement in their lives through these saving schemes, as Anifa says, *“I used part of my savings to increase my business and I have started selling cooking oil and refills. With the other share I bought grass and plastic to renovate my house because there was a lot of water coming in when it rained.”*

In the future Anifa wants to build a new house with iron roofing.



Zero Exclusion



The Zero Exclusion programme consists of two major interrelated components: (1) disability inclusive development, and (2) stigma, discrimination and mental wellbeing.

Disability Inclusive Development

Persons affected by leprosy face major barriers for equal participation in society. They are often confronted with negative attitudes and are excluded from society. They are not only stigmatized by others and by society at large, but often consider themselves less worthy because of internalized stigma. In many cases they are seriously discriminated against. Persons with disabilities also experience physical barriers, such as hindered accessibility to buildings and services.

Involving persons affected by leprosy

In order to make lasting improvements in this area it is essential that persons affected by leprosy receive correct information and become aware of their rights. We work with self-help groups and associations that are able to voice the concerns and needs of persons affected to the authorities and service providers. We also strengthen Disabled People's Organisations (DPOs) who organise self-help for people with disabilities and advocate for their rights with governments and the private sector. We believe that inclusion of persons affected by leprosy in DPOs has a positive effect on their inclusion in society and the realisation of their rights. This is why NLR, with our clear mission to improve the lives of persons affected by leprosy, collaborates with the wider disability movement.

International treaties ratified by many countries such as the UN Convention on the Rights of Persons with Disabilities and the UN Principles for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, are useful entry points to lobby for an inclusive political agenda at national and international level. We work with other ILEP organisations and the broader International Disability Movement both at national and international level to strengthen our lobby.

Our Interventions

We support, strengthen and train self-help groups, associations and DPOs to improve their work on the priorities of their members. We train and advise them to play a meaningful role in leprosy control programmes and claim rights for those affected in the local setting and also at national and international level. Making use of innovative tools and methods we try to develop new inclusive models and approaches. We stimulate learning between the programmes in different countries and successful methods are shared with other organisations, such as our ILEP partners, in order to learn from one another and promote upscaling of best practices.

Stigma, Discrimination and Mental Wellbeing

Stigma impacts persons affected by leprosy in their everyday lives. Stigma and exclusion are widespread in communities, among service providers, in the health sector, and even among persons affected by leprosy themselves.

Our Focus

Since 2019 all NLR programmes and interventions seek to take stigma and its impact into consideration and include measures to reduce it. This means minimizing barriers to case detection, to disclosure of someone's leprosy status for contact screening and SDR-PEP, to treatment adherence, to participation in self-care and self-help groups, as well as to socio-economic and political participation, access to public services and claiming rights. We aim for community and family members to accept and treat persons affected by leprosy equally and with dignity and support them to participate in social life. In addition, health staff and volunteers need to accept and treat those affected by leprosy equally. International organisations such as the WHO and ILEP are important actors who raise awareness of stigma and its consequences in leprosy programmes.

Stigma and discrimination also severely affect the mental wellbeing of persons affected by leprosy, most of whom experience depression, anxiety and/or suicidal thoughts at some point in their lives. Mental

wellbeing is a new theme for NLR and in 2019 we started exploring interventions that can reduce the impact of stigma on mental wellbeing of persons affected. In the end we would like to remove entirely the stigma and discrimination experienced by those affected and their families, that health staff treats persons affected equally and provides counselling when needed, and that identified persons in self-care and self-help groups of persons affected by leprosy are able to provide peer counselling.

Explaining what we do

We strengthen our capabilities and those of our partners, raise awareness on stigma and how it can be reduced. We have taken the first steps in developing robust approaches to reduce stigma in our projects, and we use or develop tools that help us to achieve this.

To explore ways to reduce the impact of stigma, we are developing and implementing interventions such as peer counselling, sensitisation of health staff on stigma, mental wellbeing and counselling. We are working with journalists to help reduce stigma in the media.

Under the umbrella of ILEP at international level, we have strongly supported and contributed towards the Stigma Guidelines for neglected tropical diseases, a practical guide to stigma and stigma interventions.



Zero Exclusion



Flagship Projects

Indonesia: The Mardika Project

In Indonesia NLR works in the MARDIKA Project on the concept of a disability and leprosy friendly community model. This NLR-funded project is situated in Cirebon, West Java and Jeneponto, South Sulawesi and aims to work towards inclusive village models by applying approaches that emphasize participation, equal rights, respect for differences, accessibility and non-discrimination. We work with eight local disabled people's organisations that support rights fulfilment of people with disabilities and those affected by leprosy. The partner organisations were trained by NLR to facilitate changes at community level.

From the start initiatives have been implemented to make community members and village stakeholders more aware of the rights of persons with a disability and those affected by leprosy. NLR strengthened the capacity of local partners to understand the village's development regulation and planning process. At village level the project set up inclusion groups comprising representatives of persons with disabilities and leprosy, community leaders, religious leaders, and government.

The inclusion groups strive to fulfil the rights of the target group through proposals and provides recommendations during development planning meetings and other community meetings. The groups are recognized through a village head's decree. Local government became more aware of the importance of working with these groups and provided their leaders with input and advice. As a result, the community planning process in 2019 became more inclusive and local authorities reserved budget for issues raised by the inclusive groups.

The project is working with gender-segregated data and pays specific attention to gender perspectives, but an effort still has to be made to improve the overall gender mainstreaming in this project.

Indonesia: journalist training in stigma reduction

For the first time in its history NLR carried out sensitisation training for journalists. The objective was for journalists to bring new perspectives into their news coverage that support positive public opinion regarding persons affected by leprosy, instead of feelings of pity or horror.

The journalist training was held in three high endemic provinces of Indonesia, involving approximately 25 participants from each province. Participants were not only trained in the use of linguistic choices in news reporting, but they were also invited to visit leprosy endemic villages to conduct in-depth interviews for their reports.

After completing the training journalists ceased to use words that foster stigma and encourage discrimination, such as "ex-leprosy", "lepers" or "disadvantaged people" in their on- and offline publications, newspapers, and radio broadcasts. The understanding and behaviour of journalists who attended the training had changed, so that now the news messages they provide about leprosy and disability are constructive and use appropriate language.

Another benefit of the training that emerged in one of the provinces was the large amount of news coverage given to a project. Previously it had been difficult to generate interest from journalists in the process and results.

The training also involved Health Officers from the targeted areas. As a result, they are now more focused on delivering information about leprosy and stigma in their areas through local media.

Zero Exclusion



From the field

“The only issue that bothered me was the behaviour of my family members and neighbours towards me after knowing about my disease.”

Hem Gharti Magar

Story from Nepal

“My name is Hem Gharti Magar and I am from Kailali, Province 7 of Nepal. I had numb patches down to my knee and had no sensation in my right foot. I visited a nearby medical store where I was given some medicine, but it didn’t get better and instead it spread all over my right leg. Later I noticed some abscesses around my leg, and I panicked.

One of the female Community Health Volunteers in suggested I should see someone at a health post responsible for the diagnosis and treatment of leprosy. Before I could visit the health post the person himself came to see me at my house and provided preliminary treatment before referring me to a provincial hospital for further treatment. I was diagnosed with leprosy and given medical treatment for 12 months, after which I felt much better. The only issue that bothered me was the behaviour of

my family members and neighbours towards me after knowing about my disease. I discussed it with the doctor and he conducted a one-day awareness programme in my community on leprosy and its treatment and also explained the preventive measure of giving a single dose of rifampicin to all contacts of the person affected. Now I feel more comfortable walking around my community and talking to people. My family members take good care of me and they are not scared to touch me or talk to me. I am planning to start a small business of my own very soon.”



Zero Exclusion

From the field

“I did not feel any discrimination in the health clinic. They welcomed me like an ordinary patient”

Mia

Story from Indonesia

Rap Rap village is one of 44 villages in North Sulawesi province where the Indonesian Ministry of Health and NLR began piloting the Leprosy-Friendly Village programme to reduce stigma and increase public awareness around leprosy in 2012. Today the villagers have a better knowledge of leprosy and local health workers know how to recognize its signs for early detection without discriminating against persons affected.

According to the NLR Leprosy Control Program Manager Dr. Teky Budiawan, the five-year programme at Rap Rap village was very economical because it successfully attracted participation from groups at the government and grass-root levels, including health workers, volunteers, local leaders, religious leaders and teachers.

“The programme was running for just a year when the district government decided to support its implementation until today. It shows the government’s commitment to the fight against leprosy through public

dissemination of information about leprosy and stigma reduction by the potential groups and early detection by the people who already understand the leprosy signs,” said Dr. Teky.

The village has received many visitors from other districts and provinces of Indonesia seeking to learn about best practices of the Leprosy-Friendly Village programme. The head of the North Minahasa district and the governor of North Sulawesi province have even been awarded for their success in reducing the number of new leprosy patients. In 2012 there were 18 new leprosy patients in the district. By raising awareness, the programme gradually increased the number of new leprosy patients to 65 in 2014, before decreasing them to 35 in 2016.

“The increased case finding in 2014 showed that people who became aware of leprosy signs took the initiative to visit the Aer Madidi health clinic for a check-up. And later in 2016, we saw a decrease, which indicated a success;

thanks to health workers, teachers, religious leaders and local leaders who intensively disseminated information on leprosy and the fight against stigma and self-stigma,” said Dr. Harley, Head of District Health Office.

One of those diagnosed at an early stage because of the programme was a young woman nicknamed Mia (25). Her mother took her to the health clinic in 2013 because she had two big red patches around her right eye and right arm. She thought they were just a skin allergy and was unaware it was leprosy. A health volunteer and neighbour asked her to go to the health clinic, but she did not go until her mother took her to the clinic for a consultation.

“When I was diagnosed with leprosy, I was down and sad. I locked myself in my room, but later I forced myself to get up and go to the health clinic for treatment for a year. I did not feel any discrimination in the health clinic. They welcomed me like an ordinary patient,” said Mia.



Zero Exclusion



From the field

“Today I am a very different person, I was born again”

Maria

Story from Brasil

In 1974 Maria was 20 years old and lived in a very simple house in the municipality of Labrea, close to the border between Amazonas and Rondônia. She was taken by force to a colony where persons affected by leprosy were segregated from the rest of society. *“I felt like the worst person in the world”,* said Maria, *“not even a murderer would be hunted down that way”.*

Her husband was traveling at the time and she was at this hospital for almost three months. She remembers a doctor set fire to a stool she had sat on. *“He told me not to touch anything,”* she said. *“Even our food was left on a path for us to pick up.”*

Her husband went to the colony and signed a form taking responsibility for her before leaving with Maria against the administration’s orders. *“Before the disease, we lived well and had a little shop and a bakery. Afterwards, no one bought anything that came from us, not even the machinery they wanted when we left for Rondônia”.*

Since 2010 Maria has taken part in a self-care group for persons affected by leprosy. *“Everyone treated me so well,”* she said, *“I could not imagine I would ever be someone again”.* Lacking the strength to carry on cleaning houses to earn money, Maria had struggled with the pension given to her by the government for her retirement as a person with disabilities, but her life got better through her participation in the workshops provided by the Socioeconomic Rehabilitation project. She learned how to produce jewellery using natural materials from the Amazon region. With the money earned from selling earrings, necklaces and bracelets, Maria was able to renovate her kitchen in 2019. This helped her to improve the production of natural juices, homemade bread and sandwiches, and regional sweet treats - recipes she learned in the gastronomy workshops held in 2018 in the same project.

In 2019 Maria was one of those chosen to sell products in Recife during the 10th

Hansenology (Leprosy) Symposium. It was a special moment for her because she was welcomed by many different people who wanted to hear her story. She also saw the ocean for the first time. *“Today I am a very different person”,* she said, *“I was born again”.*

“The project improves the economic situation for persons affected, but also improves their self-esteem, social participation and promotes a real inclusion in society”, said Albanete Mendonça, member of the Rondônia State Health Department and coordinator of the project.

“Changing people’s lives is not easy. But to observe clearly this change in the lives of our beneficiaries makes us very happy. Our efforts are not in vain, and we expect to attract new donors and take it further based on the results that we have achieved so far”, said Rejane Almeida, Technical Assessor of NHR Brazil.



Indicators

Multiple interventions are necessary to work towards a world free from leprosy. In the countries where we work (Brazil, India, Indonesia, Mozambique and Nepal) NLR supports active case finding of new leprosy patients and we focus on proper training of health staff, information sharing, preventive treatment, training persons affected by leprosy in self-care and working with local partners. These are indicators of our impact.

39,149



New leprosy patients detected

NLR aims to prevent, detect and treat leprosy. NLR aims for a situation in which zero new leprosy patients are detected which is captured in this indicator. Taking into account the relatively long incubation period the number of new patients detected in a year shows the effects of prevention, detection, and treatment interventions over a period of years (but it is also reflects the (case finding) activity of a programme). If patients have been detected and have started treatment, transmission of leprosy by these persons is prevented from then on. If the contacts of these patients

also received SDR PEP, the chance that they will develop and transmit leprosy decreased. The number of patients detected should also be considered within the context of a country (the endemicity, the leprosy control programme etc). An increase in number of new patients could mean that the methods for detection and or registration of patients has improved or were implemented more intensively or in new areas. A decrease may indicate reduced transmission but also reduced case finding activities.

Overall, the number of new leprosy patients detected decreased in NLR's intervention areas. A significant decrease in the number of new leprosy patients in India comes from successful leprosy case detection campaigns in earlier years and a successful SDR-PEP programme in Uttar Pradesh and West Bengal. In West Bengal the health system has become more focused to detect new leprosy patients and provide treatment. Another, more important, reason for the decrease in India is an administrative reason: the areas reported on in 2019 are different than in 2018. On the other hand, in Jharkhand the number of new leprosy patients identified in NLR's operating area increased because there was a successful case detection campaign

in 2019 resulting in more persons diagnosed with leprosy.

In other countries the increases and decreases are smaller. In Mozambique for instance there is an increase in Niassa and Zambezia, because NLR expanded its working area here and now also reported the leprosy patients found in those areas. In other areas in Mozambique, such as Nampula the number of new patients decreased due to successful leprosy control interventions in previous years.

In Nepal the number decreased slightly as well. In Brazil, the total number of new leprosy patients slightly increased, which is also reflected in a higher number of new patients in NLR's intervention areas compared to previous years.

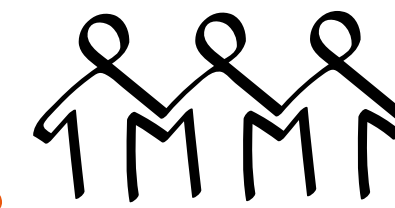
6,352



Health staff trained on leprosy

National programs, in particular health staff, play a crucial role in informing, advising and treating persons with leprosy, their contacts and the community in which they live.

42,798



People who receive information

If people are more aware of leprosy they will seek care more quickly or refer their relatives, friends and acquaintances to a health post. An informed community is less likely to discriminate against persons affected by leprosy, making those afflicted more likely to seek care. Greater awareness contributes to early diagnosis and treatment, which reduces the risk of disabilities. In addition, the chance of transmission decreases if persons affected by leprosy are treated quickly.

22,609



Persons received SDR-PEP

Reducing the number of leprosy patients was and remains an important goal for NLR to work towards for in 2019 and following years. Stopping transmission is critical to achieving this goal. Prescribing SDR-PEP to contacts will make it less likely they develop leprosy, which further reduces the chance of transmitting leprosy to others.

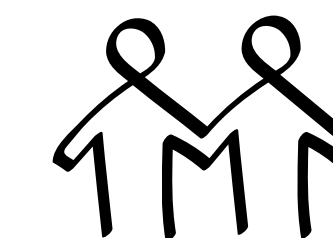
8,478



Persons affected by leprosy trained in self-care

Persons affected by leprosy may experience a loss of sensation in their hands or feet. They may not realize they have a wound, for example, and these wounds can eventually worsen, leading to permanent disability. It is therefore essential for someone who has (had) leprosy to take care in order to prevent disabilities and not to aggravate existing disabilities.

842



Groups and organisations that NLR works with

NLR supports the set-up and empowerment of local self-care and self-help groups and Disabled People's Organisations in which persons affected by leprosy can participate. By forming a group, those affected by leprosy develop a stronger position in society. They are seen by other stakeholders,

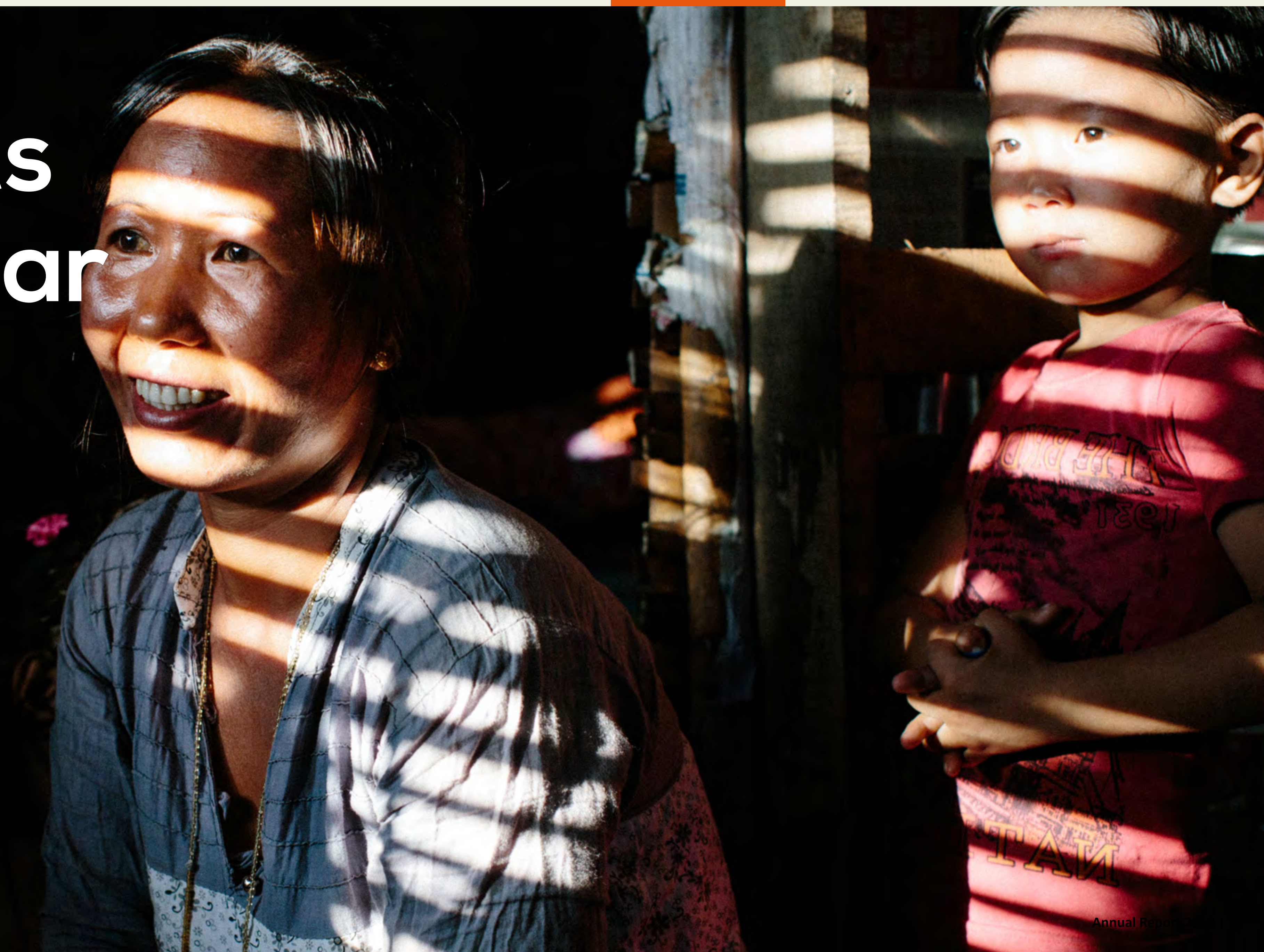
such as the local government, and can request services that meet their demands. Economic activities are also often undertaken or facilitated in these groups. In addition, these groups give persons affected by leprosy the opportunity to participate once again in all kinds of activities that take place in their community.

*Self Care Groups, Self Help Groups and Disabled Persons Organisations.

“I am thankful to NLR India, they trained me on self-care and saved me from disability. Now I am healthy and living an exclusion free social life.”

Mahendra

Highlights of the year



PEP workshop

NLR organised an international workshop on Post-Exposure Prophylaxis (PEP) for leprosy together with the Global Partnership for Zero Leprosy and Leprosy Research Initiative. The goals were to share lessons learned regarding the implementation of SDR-PEP and to define further research needed to contribute to enhancing the effectiveness and upscaling of SDR-PEP. Participants represented Ministries of Health, NGOs and research institutes from many different countries, which led to a rich exchange of experiences and fruitful output in the form of SDR-PEP implementation packages and proposal outlines for more in-depth research.

Dr. Anung Sughantono, Director General Infectious Diseases, Ministry of Health, Indonesia rightly mentioned an important lesson: *“PEP brings new hope to the health workers and local programme managers and it helps the community to realise that leprosy is preventable”*.

Ready4PEP project approved

NLR was extremely delighted to receive funding in 2019 to start the Ready4PEP project in Mozambique and Nigeria. Ready4PEP is an implementation project aiming to break the chain of leprosy transmission through active case finding and contact screening. The project’s long-term objective is to enable health services to prevent, treat and follow-up leprosy patients and their contacts. SDR-PEP will be administered to all contacts after they have been screened for leprosy. The project will be implemented in collaboration with the national leprosy control programme and ILEP partners. At the end of the project in 2022, sufficient knowledge, resources and tools should be available to start scaling up SDR-PEP to all endemic districts.





Signing transition agreements with NLR Nepal and NLR Indonesia

A historic moment took place in December 2019: NLR CEO Jan van Berkel and the chairs of the boards of NLR Nepal, Dr Prakash Wagle and of NLR Indonesia, Dr Agus Wijayanto signed the Transition Agreements and NLR Alliance Membership Agreements. This marked the start of the transition phase in which both locally registered NGOs will take over full control of programmes, staff and funding of NLR in their countries.

Urban leprosy approach

Both NLR India and NLR Indonesia implemented urban leprosy approaches in 2019 with the aim of increasing access to services and to improve quality of services for persons affected by leprosy in urban areas. This contributes to improved early case finding before impairments have developed and to improved follow-up, including completion of treatment.



Our Organisation



A solid organisational structure creates opportunities that enhance efficiency and effectiveness. Solid, that is, as opposed to rigid. Given the pace at which the world changes today, new insights and discoveries require a readiness to make changes wherever and whenever necessary. It is this readiness that enables us to serve those in need effectively, responsibly and in a sustainable manner.



Organisational Development

In 2019 we invested heavily in our IT infrastructure, starting up a complete IT renewal programme focussed on NLR's hardware and software. Our on-premise servers and desktops were moved to a cloud solution and most members of staff were provided with a laptop. Additionally, we invested in our office layout, ensuring the facilities provide an efficient and productive workplace for our staff.

In 2019 we updated our employment conditions scheme which led to a fairer and clearer compensation and recuperation policy for international travel. In addition, we updated our integrity policy and appointed a new confidential advisor.

No major flaws were reported regarding the compliance with European Union General Data Protection Regulation (GDPR). In 2019 three data incidents were reported. All incidents had limited effects and risks for violation of the Privacy rules and law. The second intermediate audit of our ISO 9001:2015 (Partos) certification was successful and reconfirmed quality, efficacy and transparency of our business processes. The three yearly certification will be renewed in 2020.

Staff

NLR's International Office is based in Amsterdam, the Netherlands, where at the end of 2019 our staff comprised 34 employees (29,1 FTE) and four volunteers working across four departments (in 2018 it was 33 employees, 26.3 FTE). In 2019 the management and execution of field activities were delegated to five professional country offices located in Mozambique (16 employees), India (68 employees), Indonesia (58 employees), Nepal (16 employees) and Brazil (29 employees). Together, these country offices employ a total of 189 employees, including research assistants (64 employees). On a special note, we welcomed three new country directors to our organisation in the same year.

Our overall absence percentage for 2019 was 6.2%, a decrease compared to 7.4% in 2018, yet still above average as well as higher than our target maximum of 4.1%. It is important to note that two members of staff were off sick for a long period of time, which accounts for this percentage. Both have fully recovered. In 2019 we changed the provider for our occupational health services.

Employee Representative Body

The Employee Representative Body is entitled to advise NLR's CEO on planned changes in the organisation, labour conditions and terms of employment that affect more than 25% of staff at the international office. In 2019 the Employee Representative Body gave its consent and positive advice on the renewal of the employment conditions scheme, the appointment of a new occupational health service and the appointment of a new workplace counsellor.

Partners and Collaborations

Working with and through partners is a major strategy that enables NLR to fulfil our mission. The most important partnerships we worked with in 2019 were the Leprosy Research Initiative (LRI), the International Federation of anti-Leprosy Associations (ILEP), the Global Partnership for Zero Leprosy (GPZL), the NTD NGO Network (NNN), Infolep, InfoNTD, the Coalition for Operational Research in NTDs (COR-NTD) and the Dutch Coalition for Disability in Development (DCDD).

Leprosy Research Initiative (LRI)

Leprosy Research Initiative (LRI) plays a key role in the funding of leprosy research and in strengthening research capacity in leprosy endemic countries. NLR manages and houses the LRI team. The CEO of NLR chairs the Executives Group, the highest decision-making body. NLR's Medical Director contributes to the Steering Committee. The NLR Supervisory Board also supervises the proceedings of the LRI. In 2019 a total of 26 ongoing research projects received funding support and five new projects were accepted for funding. The importance of the LRI was highlighted during the International Leprosy Congress in Manila in September 2019, where more than 30 research presentations were supported by LRI funded research

from the past five years. The LRI publishes its own Annual reports which can be accessed [here](#).

The International Federation of anti Leprosy Associations (ILEP)

ILEP has been our main international collaboration partner for many years. NLR staff has a leadership role in moving ILEP forward, with the NLR CEO serving as ILEP President and the NLR Medical Director serving on the ILEP Technical Commission. Several other senior staff are involved in ILEP networks liaising with colleagues in other organisations on programmes, fundraising and communication. In 2019 ILEP played a major role in consolidating the work of the GPZL by actively contributing resources and being involved in fundraising and technical initiatives.

Global Partnership for Zero Leprosy (GPZL)

GPZL is a new global initiative uniting all major stakeholders in the leprosy field. 2019 was its first full year of active operations. NLR is involved in the GPZL Leadership Team and in providing technical support to its work, supporting country programmes

and promoting leprosy research. A research priorities inventory was completed to which several NLR staff have contributed. Together with WHO, GPZL carried out the first two reviews of national leprosy control programmes. These were successfully completed in Nepal and in Morocco. The outcome, apart from a strong impetus for the programme, was a national roadmap for zero leprosy with broad support by stakeholders in each country.

The NTD NGO Network (NNN)

NLR participates actively in the NTD NGO Network (NNN), a network of more than 80 organisations across the world working on all aspects of neglected tropical disease control and management. We are particularly active in cross-cutting groups that work across multiple NTDs, for example on the diagnosis and treatment of skin related NTDs and in disease management, disability and inclusion (DMDI). DMDI also encompasses work on stigma and mental wellbeing. From September 2019, NLR's Medical Director will be engaged in the NNN Executive Committee and chairs the DMDI Cross-Cutting Group.



Infolep and InfoNTD

Key collaborations are also an integral part of Infolep and InfoNTD, two international knowledge platforms that are hosted by NLR in Amsterdam.

Infolep is the international knowledge centre for information on leprosy and leprosy related subjects. In 2019 Infolep attracted more than 26,000 unique visitors across 185 countries. The portal offers access to over 29,500 publications, with more than 1,000 publications added in 2019.

InfoNTD is an online platform that shares information, publications and tools on cross-cutting issues in Neglected Tropical Diseases (NTDs). In 2019 the portal attracted nearly 20,000 unique visitors across 191 countries, an increase of almost 40% compared to 2018.

Both Infolep and InfoNTD launched their new and improved websites in 2019. On request Infolep and InfoNTD continue to offer support, such as library services: full texts of published articles, grey literature, and assistance with literature searches. Both platforms are supported by a wide range of partners in the leprosy and NTD field.

Coalition for Operational Research in NTDs (COR-NTD)

COR-NTD is a network of researchers in NTDs. It also administers a funding mechanism for NTD research

through which NLR had two multi-NTD projects approved in 2019. COR-NTD organises an annual research conference in the US or Canada where researchers report on progress and needs in NTD. In November 2019, NLR co-organised a Breakout session on PEP research, which was well received. Another feature of the COR-NTD meetings is the Innovation Lab where organisations can showcase new tools or products for work in NTDs. NLR presented the Skin Games, a training tool for diagnosis of skin related NTDs developed to facilitate training in the use of the SkinApp.

Dutch Coalition for Disability in Development (DCDD)

NLR’s Programmes Director is chairing DCDD which comprises more than 20 organisations and professionals who lobby the Dutch government for better policies for inclusion of people with disabilities, including those affected by leprosy. In many countries persons affected by leprosy join hands with those with disabilities, and together they stand stronger in the fight for their rights and reduction of stigma.





Integrity Management

In 2018 we mainly focused on enhancing our internal mechanisms and awareness on issues and complaints related to integrity. Following on from this, we used 2019 to further improve our integrity policy and framework by drafting and implementing an overall integrity policy. To ensure implementation, we appointed an integrity officer for the organisation. For the office in Amsterdam a new confidential advisor was appointed and introduced to the staff.

In line with the NLR Anti-Fraud & Anti-Corruption Policy, which applies to all NLR offices. NLR's field projects are monitored and evaluated on a regular basis, not only by our Country Offices but also by internal and external experts.

This ensures our spending lines up with our strategy and accountability principles. All Country Offices undergo an annual financial audit, performed by an external auditor. No major flaws were identified in 2019.

As in 2018, all existing staff in 2019 have refreshed their understanding of our Code of Conduct and related regulations by discussing examples of fictional but realistic cases around integrity issues. This session was conducted with the office staff and in a separate session with the supervisory board of NLR, to enhance the awareness of integrity risks in the organisation also at their level of supervision.

The following integrity policies and protocols are in place and together they form NLR's integrity framework:

- Overall integrity policy
- Code of Conduct
- Complaint & Whistle-blower Policy
- Anti-Fraud & Anti-Corruption Policy
- Policy on Inappropriate Behaviour
- Communication Policy & Crisis Protocol
- Annual Risk Analysis

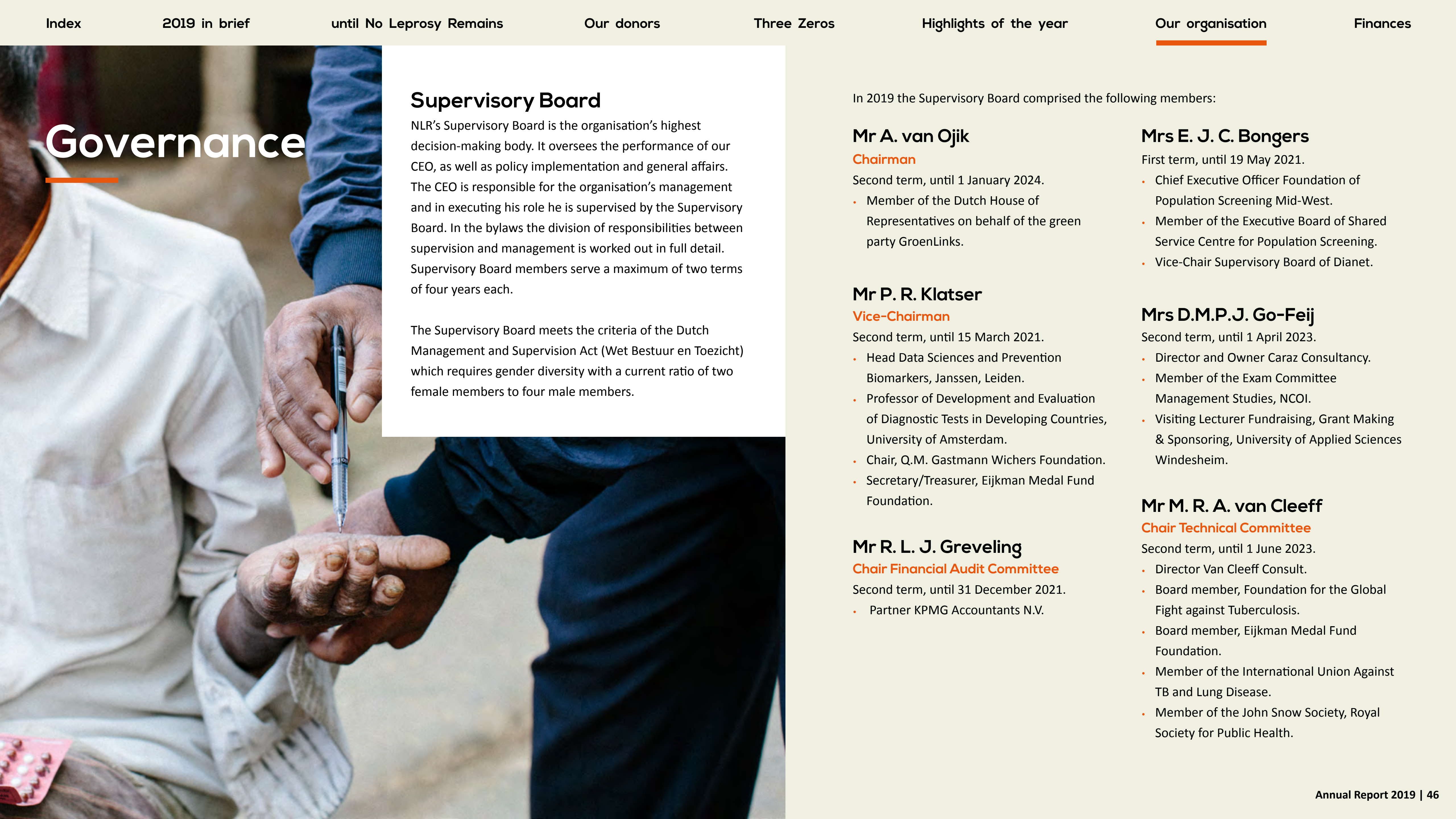
2019 integrity issues report

With an effective integrity system in place, integrity issues were reported and handled appropriately.

In 2019 two issues were reported from the Country Offices: first, a complaint about sexual harassment which was investigated by an independent committee which concluded the working culture at the Country Office concerned was too informal, leading to misunderstandings and the feeling that personal borders were crossed. The investigating committee advised on how to improve the culture of the organisation. The Country Director implemented this advice during 2019.

In addition, we finalised the investigation of a complaint about management style that was made by a dismissed staff member of staff in one of our Country Offices in 2018. The complaints committee concluded that the management style could improve and be more human oriented. A new management style has been introduced in this Country Office and HR policies have been adjusted to safeguard this.

There was also a suspicion of fraud in relation to the purchase of IT equipment in one Country Office. The case was investigated, but the fraud could not be proven. Rules and regulations were formulated more strictly to prevent similar situations in the future.



Governance

Supervisory Board

NLR’s Supervisory Board is the organisation’s highest decision-making body. It oversees the performance of our CEO, as well as policy implementation and general affairs. The CEO is responsible for the organisation’s management and in executing his role he is supervised by the Supervisory Board. In the bylaws the division of responsibilities between supervision and management is worked out in full detail. Supervisory Board members serve a maximum of two terms of four years each.

The Supervisory Board meets the criteria of the Dutch Management and Supervision Act (Wet Bestuur en Toezicht) which requires gender diversity with a current ratio of two female members to four male members.

In 2019 the Supervisory Board comprised the following members:

Mr A. van Ojik

Chairman

Second term, until 1 January 2024.

- Member of the Dutch House of Representatives on behalf of the green party GroenLinks.

Mr P. R. Klatser

Vice-Chairman

Second term, until 15 March 2021.

- Head Data Sciences and Prevention Biomarkers, Janssen, Leiden.
- Professor of Development and Evaluation of Diagnostic Tests in Developing Countries, University of Amsterdam.
- Chair, Q.M. Gastmann Wichers Foundation.
- Secretary/Treasurer, Eijkman Medal Fund Foundation.

Mr R. L. J. Greveling

Chair Financial Audit Committee

Second term, until 31 December 2021.

- Partner KPMG Accountants N.V.

Mrs E. J. C. Bongers

First term, until 19 May 2021.

- Chief Executive Officer Foundation of Population Screening Mid-West.
- Member of the Executive Board of Shared Service Centre for Population Screening.
- Vice-Chair Supervisory Board of Dianet.

Mrs D.M.P.J. Go-Feij

Second term, until 1 April 2023.

- Director and Owner Caraz Consultancy.
- Member of the Exam Committee Management Studies, NCOI.
- Visiting Lecturer Fundraising, Grant Making & Sponsoring, University of Applied Sciences Windesheim.

Mr M. R. A. van Cleeff

Chair Technical Committee

Second term, until 1 June 2023.

- Director Van Cleeff Consult.
- Board member, Foundation for the Global Fight against Tuberculosis.
- Board member, Eijkman Medal Fund Foundation.
- Member of the International Union Against TB and Lung Disease.
- Member of the John Snow Society, Royal Society for Public Health.

Proceedings of the Supervisory Board in 2019

During their annual visit of the International Office and meetings with NLR’s staff in September 2019, the Supervisory Board collected additional information about the International Office’s culture and activities to supplement information already provided by the Managing Director.

To understand NLR’s work and our impact, each member of the Supervisory Board is expected to visit an NLR field programme at least once during their term. In 2019 one member accompanied the CEO on a visit to the Country Office and project sites in India. Within the framework of decentralisation, they interacted with the new board of the locally registered NGO NLR India Foundation and discussed governance issues of the NLR Alliance within the Indian legal context. Another member of the Supervisory Board attended the International Leprosy Congress in Manila to get an updated impression of the current state of leprosy policies and leprosy research, as well as the contributions and roles of NLR and the LRI in the international leprosy world.

In March 2019 the Supervisory Board evaluated its own functioning. In their 2019 evaluation, the Supervisory Board concluded it had sufficient access to information to supervise the CEO. The Board also outlined the agenda for its 2019 and 2020 meetings. To put a stronger emphasis on supervising the impact of NLR’s programmes, the Supervisory Board appointed a Technical Commission to monitor the efficiency and efficacy of NLR’s expenditures on programmes and technical projects. The Committee held its first meeting in November 2019 and will meet bi-annually to prepare advice to the Supervisory Board on approving strategies, annual plans and annual reports.

In 2019 the Supervisory Board addressed the following six items and discussed various issues:

- Progress Reports performed by the Managing Director on the execution of the annual plan and budget were discussed on a quarterly basis.
- The progress of the NLR 2020 decentralisation project was discussed during an extra meeting in January and during every quarterly meeting.
- In May the Board approved the 2018 Annual Reports of NLR and the LRI.
- At its December meeting, the Board approved the Multi Annual Strategy 2020-2022 of NLR and the 2020 Annual Plans and Budgets of NLR and the LRI.
- In addition to its quarterly meetings, in its annual strategy meeting in September the Board discussed and approved the new marketing and fundraising strategy and the integrity policies and instruments.
- The Supervisory Board evaluated the CEO’s performance and the cooperation between the Board and the CEO.

Director’s remuneration

The Supervisory Board is responsible for NLR’s remuneration policy and determines the salary of our CEO. NLR complies with the requirements of The Netherlands Fundraising Regulator (CBF). Compared to positions of similar complexity and responsibility, the Supervisory Board considers the Managing Director’s current remuneration fair and reasonable.

Furthermore, the Supervisory Board regards the position of NLR’s Managing Director as more than a fulltime job. It is a role with great responsibility that requires a high profile, professional performance. The Managing Director is in charge of an international organisation that raises over € 10,000,000 per year, employs 34 people in Amsterdam and 189 in the Country Offices, receives the support of approximately 43,116 donors and 350 volunteers, and cooperates with many international partners, including health ministries, scientists, companies and other NGOs.

Every three years the Supervisory Board reviews the remuneration of the CEO, with the most recent review taking place in 2019. The Board approved the updated job description of the CEO and concluded that the remuneration as per 2020 should be adjusted in accordance with the regulations. The 2019 annual remuneration of CEO Mr Jan van Berkel was € 120.000 (1 FTE/12 months). Van Berkel donated his remuneration of € 7.500 as chair of Goede Doelen Nederland to NLR. For further details, see Annual Accounts of NLR.

Organisational Perspective

Challenges and dilemmas

The successful introduction in 2019 of recruiting committed individual donors by door-to door campaigns will be further deployed in 2020 to strengthen the structural foundation of our unearmarked donations. They are key to secure our ability to do research and to introduce pilots of new and improved methods and medication to prevent leprosy. Legacies remain an important additional source of income, for which we are immensely grateful.

NLR operates on a carbon-neutral basis. In 2019, our CO2 emissions from air travel and printing were 4% lower than in 2018. They were compensated by contributions to sustainable energy projects.

COVID -19

COVID -19 and economic recession may affect donations in future, and change the priorities of institutional donors funding leprosy and other public health programmes. Not all institutional donors show flexibility in response to delayed implementation and possible extension of projects durations. NLR will raise additional funds or create reserves where necessary to cover future costs of such extensions, to secure completion of projects.

In 2020 COVID-19 and government measures have limited the access to the field for all NLR teams, thus decreasing possibilities to implement programmes and projects substantially. Though our teams initiated COVID information and education campaigns in their working areas and assisted in emergency aid for our beneficiaries, the regular work suffered delays and backlogs. At the moment of publication of this Annual Report 2019 it is very likely that COVID will

also in 2021 have its negative effects on programme implementation. In 2020 strategic options to limit the damage and seek alternative ways to realise the NLR mission are discussed to be implemented from autumn 2020 onwards into 2021.

Opportunities ahead

The growth of resources provided by Institutional donors in 2019 enabled us to launch more multi-country projects coordinated from our International Office in Amsterdam.

In 2020 we will continue our leading international role in innovative preventive treatment through SDR-PEP and remain an active partner in ILEP and the Global Partnership for Zero Leprosy. This ambitious, all-stakeholder partnership is a unique opportunity to unite and align all the partners that are needed to develop and implement international and national roadmaps to zero leprosy, and to fill in the remaining gaps in our understanding of the disease through high quality research in the years ahead.

Finances

Result 2019 in short

The annual accounts are a consolidation of the NLR annual accounts and the Leprosy Research Initiative (LRI) annual accounts. The 2019 total consolidated income was € 8,3 million (2018: € 11,2 million), while € 9,0 million was budgeted. Total expenses were € 11,8 million (2018: € 10,5 million), while € 11,8 million was budgeted.

The overall 2019 negative result, after adding the positive result on our financial investments (€ 0,9 million), is € 2,5 million (2018: € 0,5 million positive result) which was subtracted from our earmarked funds and reserves. We budgeted a negative result of € 2,6 million.

See annual accounts for more information on our finance.

Financial Highlights 2019: income

Overall income

Total income in 2019 stood lower than budget as well as lower than last year. Our income from individuals was higher than budgeted but lower than 2018, when income from legacies was high. Again we were happy to receive our annual contribution of € 1,35 million as beneficiary of the Dutch Postcode Lottery. Our income from other organisations and governments totalled € 2,5 million, which is lower than budget due to the fact that institutional donor income expected for 2019 moved to 2020. From our financial investments we gained € 1,0 million in positive results.

Fundraising in the Netherlands

We anticipated in the 2019 budget that income from our own fundraising (excluding income from legacies) would increase to € 2,7 million. Actual income amounted over € 2,5 million due to the fact that incidental donations decreased substantially. Thanks to our successful door-to-door campaign, the number of committed donors grew in 2019, thus strengthening the structural income perspectives for the years ahead.

Legacies

In line with previous years we budgeted our 2019 income from legacies as € 1,4 million. We received € 1,9 million in 2019. The number of legacies received did not decrease, but the average size of the individual legacies was smaller than 2018, when we received an exceptional high legacies income of € 4,1 million.

Dutch Ministry of Foreign Affairs

Between 2017 and the end of 2019 an amount of € 360,900 from the Ministry of Foreign Trade and Development Cooperation under the Accountability Fund, was received for the programme LEAP in Indonesia: Local Economic development of people with disability through active Advocacy for an inclusive Policy. In 2019 we've recognised € 178,000 as income covering expenditure for our planned activities.

EDCTP

In 2018, a total amount of almost € 3,2 million was awarded by the European & Developing Countries Clinical Trials Partnership (EDCTP) for the PEP4LEP project. This multi-partner project will be implemented during a period of 52 months. In 2018, the first transfer of nearly € 1,6 million was received by NLR, as programme coordinator, of which almost half was spent in that same year. In 2019 we spent close to € 0,5 million. The remainder is carried over to 2020.



Financial Highlights 2019: expenses

Overall expenditure

Total expenditure in 2019 is higher than budget and higher than last year. In 2019 we spent € 9,9 million on our objectives, which is 84% of our total expenditures (2018: 83%).

Field programmes

Direct expenses for field programmes amounted to € 3,7 million (2018: € 3,3 million). The budget for 2019 was € 5,3 million.

The expenses on supporting projects (€ 0,9 million) were higher than last year (€ 1,1 million) due to higher allocated support costs as well as investments in decentralization of country offices and programmes through the NLR 2020 programme.

The research expenses include research funding by the LRI in 2019. They amounted to € 2,6 million in 2019 against a budget of € 1,6 million.

NLR 2020

In 2019 we have spent an amount of € 0,7 million from our earmarked investment reserve on the NLR 2020 programme, aiming at transforming our branch offices into local NGOs that are embedded in their local contexts.

Other expenses from our reserves

Other expenses from our investment reserves, amounting to € 1,0 million, included investments in both Fundraising (€ 0,3 million), IT improvements on both hardware as development of new and existing software solutions (€ 0,2 million) and € 0,3 million was spent on programmatic and medical technical investments. Also, we made investments in the transition plans for our former offices in Nigeria and Mekong. Both continue part of their operations as national NGOs with external funding.

Expenses from earmarked funds

For the five-year Dutch Postcode Lottery funded project “Stop the Transmission of Leprosy!” we spent an amount of € 1,4 million in 2019 against € 0,9 million in 2018.

Information and awareness raising

The total expenses on information and awareness raising were € 0,6 million while € 0,5 million was budgeted. These expenditures were in line with last years’ expenditure.

Fundraising

Expenditure on fundraising was € 1,2 million instead of the budgeted € 0,9 million. These higher expenses to increase the amount of individual donors through our door-to-door activities as a result of the decision to allocate part of the reserves to further invest in fundraising. The total spending on our own fundraising in relation to the total raised income amounted to 14% (2018: 12%).

We invested € 300.000 in attracting more committed donors, to secure future fundraising income to enable continuation and expansion of our programmes in endemic countries. We piloted with door-to-door fundraising, with positive results. Thus investing from the reserves we welcomed 2.000 new individual donors, who committed a fixed monthly contribution to NLR. This campaign is continued in 2020.

We also invested in a first try-out of an online information campaign to raise awareness among the Dutch public about the urgency of leprosy and its related effects.



Other points of interest

Consolidated annual account

Since 1 June 2015, the Leprosy Research Initiative (LRI) is registered as a Foundation under Dutch law. The LRI is a unique model of cooperation and coordination in the funding of research. Members of LRI are American Leprosy Missions (ALM), German Leprosy Relief Association (GLRA), effect:hope, The Leprosy Mission International (TLMI) and NLR. Jointly they are committed to the fight against leprosy and have combined their funding for leprosy-related research in the joint LRI fund. NLR manages the LRI operations, implementing the decisions of the LRI Executives Group and supervised by the Supervisory Board of NLR. The LRI annual accounts 2019 have therefore been consolidated with the NLR annual accounts 2019.

Financial income and expenses

The balance of financial income and expenses regarding invested reserves was € 1,0 million in total. A very substantial increase against budget (€ 0,2 million) and last year (loss of € 0,2 million).

The portfolio is managed by an external agency. Investments are in line with the NLR investment policy, which prescribes investments in sustainable, socially responsible and low-risk bonds. Adherence to this policy by the investment manager is checked twice a year. In 2019, the Supervisory Board approved the extension of the portfolio to include a limited share of investments in sustainable, socially responsible shares, as the decline of interest rates of bonds threatened the value of the principal. The yield on the portfolio was 8,0% (2018: minus 1,9%).

Reserves and funds

NLR's reserve policy is closely linked to the long-term relationship with our partners in endemic countries. We want to enable them to rely on the fact that NLR can fulfil its commitments. For this reason we have an earmarked reserve for project funding in the coming years. This project reserve amounts to € 4,5 million.

The other earmarked reserve for investments, priorities and transition, contains funds that are approved for internal investments in innovation, capacity building, as well as the transition of our country offices into NGOs under the NLR 2020 programme. The total amount of this earmarked reserve at the end of 2019 is € 2,0 million.

NLR holds an earmarked fund for the Dutch Postcode Lottery funded project 'Stop the Transmission of Leprosy'. The balance of this fund at the end of 2019 is € 6,6 million.

The continuity reserve is kept for continuity risks for the organisation itself. According to the guidelines of the CBF, this reserve can amount to a maximum of 1,5 times the annual organisational costs. NLR aims at a continuity reserve of between 0,5 and 1 times the yearly costs of the work organisation. At the end of 2019, the continuity reserve was € 4,5 million, which is the desired maximum of 1,0 times the annual organisation costs.



Beyond 2019

As always, the budget for 2020 is a balanced one. For 2020 we are aiming to increase our income further focusing on both individual donors as well as institutional funders. The total budgeted income for 2020 is € 8,1 million.

In order to finance our ambitious plans for 2020 we are budgeting a total expenditure amount of € 11,8 million. This will allow us to invest further in both our expenditures on objectives as well as strengthening our fundraising and organisational structure. In this amount a total of € 3,5 million is budgeted to be spent from earmarked reserves and funds.

At the date of publication of this Annual Report the world is struggling with the COVID-19 infection and related lockdowns. We see and expect no immediate substantial effect on our income 2020, as donors sustain in showing their strong loyalty to our mission. Expenses will go down, due to lockdowns hampering field work in almost all programme countries. Part of this budget is reallocated to COVID related expenses to protect and support our beneficiaries during this crisis and to contribute to COVID information campaigns and health system support, especially in remote areas, where we run our leprosy programmes. The projections for 2021 and 2022, linked to the Multi-Annual Strategy, are roughly in line with the 2020 budget, though long term impact of COVID-19 is uncertain. This will be reviewed by the end of 2020.

NLR Budget 2020

This is the approved NLR 2020 budget. For the separate 2020 LRI budget, please refer to LRI’s annual accounts of 2019.

Income	€ 1,000s
Income from individuals	4,151
Income from companies	-
Income from lotteries	1,350
Grants from governments	523
Income from other non-profit organisations	1,629
Sum of raised income	7,653
Income in return of goods and services	10
Other income	440

Total income	8,103
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Expenses	€ 1,000s
Leprosy control and disability programme activities	6,837
Co-ordination and medical advice	2,085
Information and awareness raising	803
Sum of expenses on objectives	9,725
Fundraising expenses	1,152
Management and administration	902

Total expenses	11,779
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Financial Income and Expenses	200
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Balance of income and expenses	-3,476
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Destination of the balance of income and expenses	
Additional Withdrawal from Continuity reserve	-
Additional Withdrawal from Earmarked reserves	-1,429
Additional Withdrawal from Earmarked funds	-2,047
	-3,476

Colophon

NLR (known as Leprastichting), registered under Chamber of Commerce Number 41199723, resides at Wibautstraat 137k, 1097 DN in Amsterdam, The Netherlands.

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until
No Leprosy Remains
