



Annual Report 2018

Working together to fight leprosy

Working together to fight leprosy



**Towards a world free of leprosy
and exclusion due to disabilities** ↗
** number of new leprosy cases detected worldwide*

Editorial

2018: a year of joining hands

An old African proverb says: “If you want to go fast, go alone. If you want to go far, go together.” It is this proverb that summarises our 2018. We choose to go together. Because the fight against leprosy is tough and tedious. To reach zero leprosy, we must go far!

In 2018, a big chunk of our efforts went into partnering and collaboration. The absolute highlight in collaboration for zero leprosy was the launch of the Global Partnership for Zero Leprosy at World Leprosy Day 2018. All stakeholders in leprosy joined hands: national leprosy programmes, researchers, the World Health Organization, persons affected by leprosy, donors, and last but not least the concerned NGOs, represented by the International Federation of Anti-Leprosy Associations (ILEP). Key to this partnership is the understanding that reaching Zero Leprosy is too big a challenge for any of the individual leprosy stakeholders to realise. A serious attempt at this ambition, begs collaboration.

NLR is, and was in 2018, an active partner in and initiator of collaborations and partnerships. NLR’s CEO Jan van Berkel was re-elected by ILEP’s members as their President; technical NLR staff contributed to ILEP’s Technical Commission. Conjointly with all of its thirteen members, ILEP launched another successful World Leprosy Day campaign aiming at triple zero: Zero Transmission, Zero Disabilities, and Zero Discrimination.

Moreover, 2018 saw an external review of the Leprosy Research Initiative (LRI) take place, another important collaborative venture that was co-initiated by NLR and celebrated its fifth anniversary in the same year. The LRI, now counting eight actively participating (co-) funding members, is managed and supervised by NLR. The external auditors commended the LRI for its impact on leprosy-related research and for the objective, fair, and clearly structured selection process.

The two important and frequently used online portals Infolep and InfoNTD, give access to over 30,000 scientific articles and provide support to researchers and fieldworkers. The portals are supported by a total of fifteen NGOs and coordinated from our office in Amsterdam, the Netherlands.

The Dutch Coalition for Disability and Development (DCDD) is a joint effort at prioritising disability inclusion on the Dutch Government’s agenda for international development cooperation. Starting from 2018, NLRs Director of Programmes chairs the DCDD.

In 2018, the NLR logo rightly illustrated our conviction that joining hands makes all the difference.



Bram van Ojik
Chair, Supervisory Board



Jan van Berkel
CEO



“ In 2018, the NLR logo rightly illustrated our conviction that joining hands makes all the difference.”

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2018 in brief



In 2018, NLR worked in Mozambique, India, Indonesia, Nepal, and Brazil. We continued phasing out our former programmes in Nigeria and the Mekong Region.

All of our programmes are aimed at promoting and supporting health, ability, and full inclusion in society for persons affected by leprosy or living with disabilities. To achieve this, we focus on four priority programmes:

1 Stop transmission of leprosy

2 Combined approaches to prevention and management of disability

3 Disability inclusive development

4 Reduction of stigma and discrimination

These priorities are in line with:

The Global Leprosy Strategy

“Accelerating towards a leprosy-free world” of the **World Health Organization (WHO)**

The Triple Zero campaign

“Zero Transmission, Zero Disabilities, Zero Discrimination” of the **International Federation of Anti-Leprosy Associations (ILEP)**

The Global Partnership for Zero Leprosy

“To facilitate alignment of the leprosy community and to accelerate effective collaborative action toward the goal”

Our results

Our worldwide achievements in 2018



48,176 new leprosy cases were found, diagnosed, and treated across our programme areas



54,699 direct contacts of new leprosy patients were given a single dose of rifampicin to reduce their risk of developing leprosy by 50-60%



7,165 health workers, government health staff, community volunteers and accredited social health activists (ASHAs) were trained on leprosy



2,041,055 people were informed and educated on leprosy to raise awareness



8,810 people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



18,463 community members were informed and educated about general disabilities to raise awareness



664 existing self-care groups (formed before 2018) and **30** newly formed self-care groups were supported



2,818 persons disabled by leprosy and other diseases were trained in self-care to help prevent (the worsening of) disabilities



461 lives were improved with reconstructive surgery



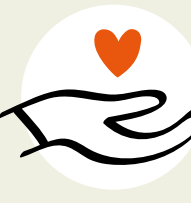
36 Disabled People's Organisations received assistance to promote participation of people with leprosy-related disabilities



831 people were provided with leadership training to guide and support others and groups



784 people received vocational training to learn a trade



1,675 children of leprosy-affected persons received financial support for their education



393 people received a microcredit to help them become self-employed



1,053 persons with disabilities were helped to stand up for their rights

Our income and expenses

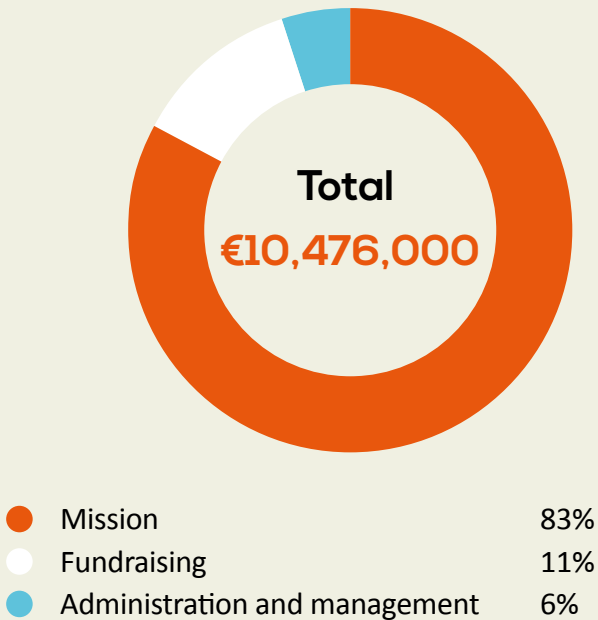
How did we spend our money in 2018?

Over the past year, we received a total of €11,2 million euros of income. This continued support is vital as it enables us to continue our fight against leprosy and change the lives of those affected. Throughout the Netherlands, we received support from 44,862 donors, around 350 volunteers, and many dedicated supporters taking part in different fundraising activities. Furthermore, we received additional funding from 16 institutional partners, which include governments and foundations. A massive part of this funding we received from the Dutch Postcode Lottery and its participants.

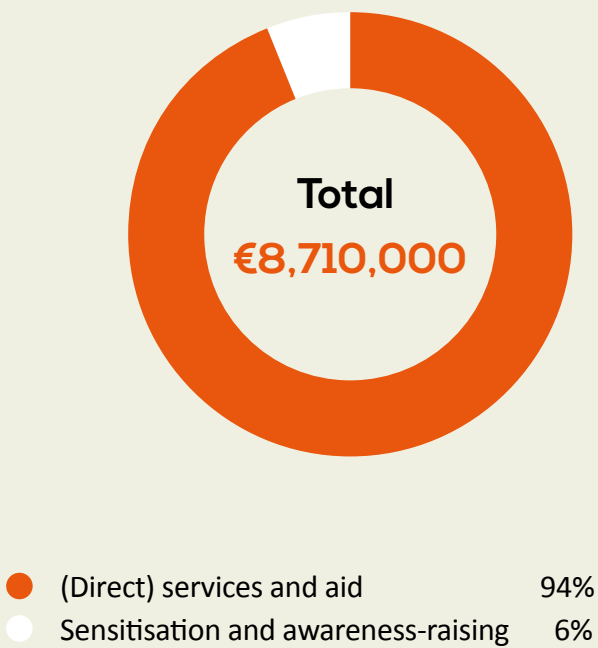
Other details concerning our income and expenses are shown in the Annual Accounts.

Annual accounts

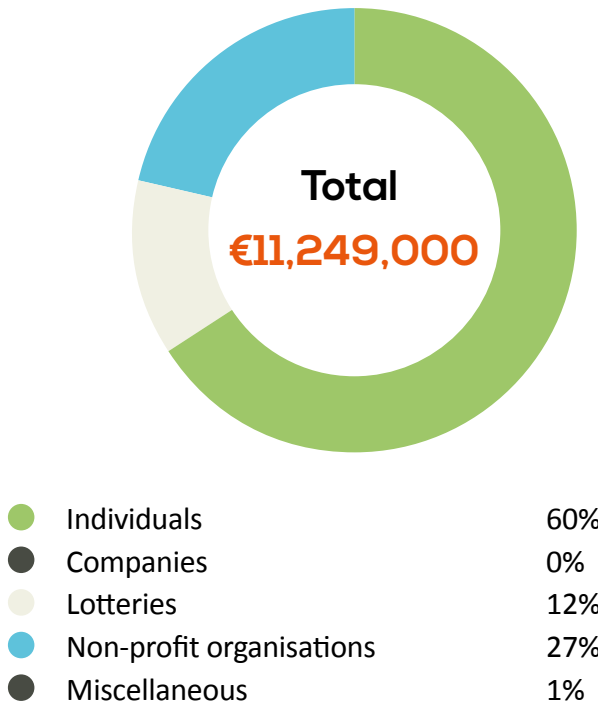
This is what we spent in 2018



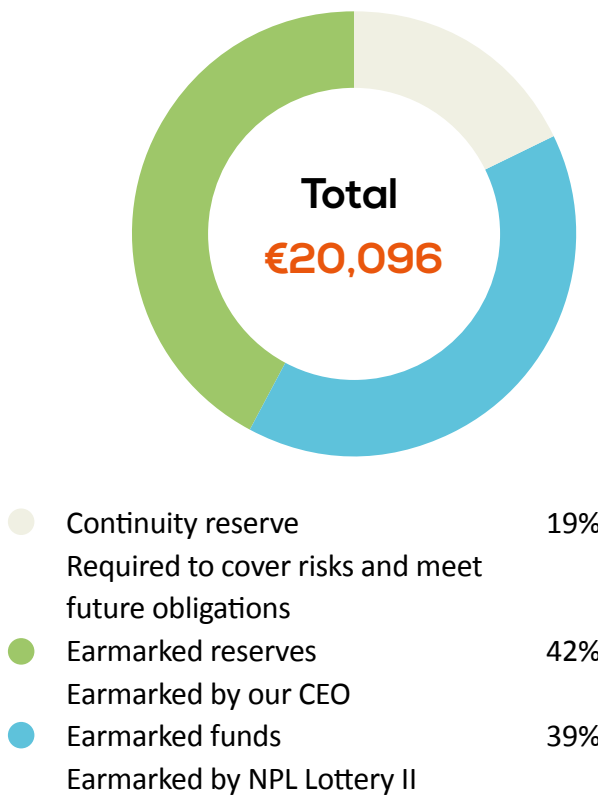
This is what we spent on our mission in 2018



This was our income in 2018



In support of our mission, these were our reserves and funds in 2018



Highlights in 2018

The third version of the SkinApp was developed as well as a validation process kick off.

The process is the first step in bringing country-specific versions to Indonesia, Brazil, Mozambique, and Nepal, among other countries.

We revamped and completely redesigned both our Dutch and international websites.

The new websites feature a captivating layout, are user-friendly on desktop, tablet, and smartphone, easy to navigate and read, and contain tale-telling photographic and video graphic imagery.

NLR hosted a donor event for private donors who donated towards a project in Mozambique.

With seventy donors attending, the event provided a fruitful social setting to meet donors face-to-face and inform them about the project – which thanks its encouraging progress to their contributions.

NLR is one of the pioneers introducing the preventive treatment single dose rifampicin to Africa. Our research project, PEP4LEP, is funded by the European and Developing Countries Clinical Trials Partnership (EDCTP).

The project compares the effectiveness and feasibility of a skin camp intervention to a health centre-based intervention and is implemented as a trial in Mozambique, Ethiopia, and Tanzania.

The World Health Organization published its first official guidelines on leprosy.

More importantly, the guidelines formally recommend single dose rifampicin as a preventive treatment for direct contacts of leprosy patients. NLR played an active role in performing the research and pilot project LPEP (Leprosy Post-Exposure Prophylaxis) that led to the guidelines. The publication heralds a new era: leprosy as a preventable disease.

We played a major role in organising the Indian government-run stigma reduction “SPARSH” campaign throughout the country including NLR supported states.

Among other things, video clips on leprosy detection and treatment called “LepClips” as well as posters – both developed by NLR India – were used during the campaign.



Our vision, mission & strategy

Our vision

We envision a world free of leprosy and exclusion due to disabilities.

Our mission

NLR promotes and supports health, ability, and full inclusion in society for persons affected by leprosy or living with disabilities.

Our strategy

NLR works towards its goals by:

- Working with governments, non-governmental organisations (NGOs), research institutions, and Disabled People's Organisations to promote access and quality of services by means of training, expert advice, research, and innovation.
- Strengthening capacity through training, expert advice, research, and innovation.
- Developing policies and programmes in line with the United Nations Convention on the Rights of Persons with Disabilities, aiming to combat neglected tropical diseases and their consequences and contribute to poverty reduction, the promotion of human rights, and social inclusion of persons affected by leprosy and persons with disabilities.
- Integrating leprosy work with other neglected tropical diseases and disability work.
- Lobbying to keep leprosy and disability inclusion on policy agendas at all levels.
- Facilitating rehabilitation services, reduction of stigma, and the promotion of self-care and empowerment.

Our priority programmes

To give greater direction to our work, we focus our attention on the four most pressing issues in the fight against leprosy. We call these our priority programmes. They are implemented in multiple countries simultaneously, making our Country Offices work closely together.

Our priority programmes are in line with the Global Leprosy Strategy (“Accelerating towards a leprosy-free world”) of the World Health Organization and the Triple Zero campaign (“Zero Transmission, Zero Disabilities, Zero Discrimination”) of the International Federation of Anti-Leprosy Associations (ILEP).

1 Stop transmission of leprosy

2 Combined approaches to prevention and management of disability

3 Disability inclusive development

4 Reduction of stigma and discrimination

1

Priority programme

Stop transmission of leprosy

Elimination of leprosy is only possible if we can stop the transmission of the leprosy bacilli.

What we accomplished in 2018

With the support of the European and Developing Countries Clinical Trials Partnership (EDCTP) and the Leprosy Research Initiative (LRI), NLR launched the PEP4LEP research project in Mozambique, Ethiopia, and Tanzania. This project is executed in conjunction with our project partner German Leprosy and Relief Association (GLRA). PEP4LEP builds on the knowledge acquired by the Leprosy Post-Exposure Prophylaxis (LPEP) programme, which was set up to test the feasibility and acceptability of a single dose of rifampicin as a preventative treatment for leprosy.

Rifampicin is given to direct contacts of newly diagnosed leprosy cases to decrease their risk of developing the disease. In the countries involved, PEP4LEP examines whether single dose rifampicin is more efficiently provided at health centres or in skin camp settings. PEP4LEP is our first activity to take the success of the LPEP programme to Africa.

The LPEP programme itself is moving towards completion. NLR has implemented the programme in Indonesia, India, Nepal, and Cambodia. Over the five years that LPEP ran, more than 100,000 direct contacts of new leprosy patients were administered single dose rifampicin. With NLR’s help, governments in India and Nepal are now upscaling LPEP to additional districts.

The success of LPEP depends on the detection of new leprosy cases. In order to increase chances of health workers detecting the disease, NLR developed the SkinApp. Based on pictures and descriptions, this smartphone application helps health workers identify skin diseases – including leprosy – where workers might otherwise lack the knowledge required to reach an accurate diagnosis.

Our “Stop the transmission of leprosy!” project is funded by the Dutch Postcode Lottery through its “Dream Fund”. Mapping studies (to identify clusters of leprosy patients) and perception studies (to understand how communities perceive leprosy and its stigma) were performed to develop community education and information materials. In 2019, the first doses of PEP++ (a combination of drugs that should lead to an over 90% reduction of leprosy transmission) will be handed out.

2 **Priority programme** Combined approaches to prevention and management of disability



Because leprosy shares many symptoms with other neglected tropical diseases and diseases that cause nerve damage (such as diabetes), the physical needs of those affected are similar. By implementing combined approaches, we can tackle disabilities more effectively and efficiently.

What we accomplished in 2018

We use our experience in leprosy to integrate with other disease programmes. We do this in India and Mozambique. In Zambezia province, Mozambique, we finalised the project “Improving disability prevention and contributing to disability reduction in communities affected by lymphatic filariasis and leprosy.” We provided patients with treatment and disability services through combined self-care groups, assistive devices, and reconstructive surgery. Working in groups that combine patients of different diseases has led to a reduction of the discomfort and mental burden caused by stigma.

3 **Priority programme** Disability-inclusive development



Our disability-inclusive development initiatives aim to ensure that people with disabilities caused by leprosy and other diseases can fully and actively participate in society on an equal basis.

What we accomplished in 2018

To stimulate inclusion and raise awareness, we worked with disabled people and their communities. This reinforced the active participation of disabled people in their societies. Persons affected by leprosy organised themselves and became members of Disabled People's Organisations. As a result, they communicated their needs more successfully and benefited from the work done by Disabled People's Organisations. By working with Disabled People's Organisations, leprosy-related stigma decreased. Furthermore, Disabled People's Organisations effectively lobbied their local and national governments for more accessible services for people with disabilities, including those affected by leprosy.

NLR also supported self-help groups. We launched for example an inclusive agricultural and healthcare programme for disabled people in rural Mozambique. In Nepal, we work with Disability-Friendly Communities. In these communities, all relevant stakeholders become responsible and accountable towards fulfilling the rights of persons with disabilities (including those disabled by leprosy) as provisioned in laws, policies, and programmes.

The country pages in this annual report tell more about these various projects.

4

Priority programme

Reduction of stigma and discrimination

It is not just the physical effects of leprosy that devastate lives. Victims experience ruthless prejudice, cutting them off from their communities, hindering their full participation in society, and causing many to feel ashamed and worthless. The terrible stigma attached to leprosy also forms a barrier to treatment. Many that contract the disease hide away, avoiding diagnosis for fear of its social and economic consequences. The counterproductive effects of belated diagnosis can only underpin how important the fight against stigma and discrimination continues to be.

What we accomplished in 2018

2018 kick-started the development of this priority programme. NLR's International Office organised an international working meeting. By means of exchanging experiences, tools, and ideas between our Country Offices and external partners, we have defined common interests and opportunities.

“ The reduction of stigma will become an integrated part of all priority programmes. ”



2018 evaluated

The year in review

2018's most promising event was the launch of the Global Partnership for Zero Leprosy. This uniquely collaborative commitment to ending leprosy acknowledges that the challenge is too big for any of the individual stakeholders to reach in their own strength.

NLR has been actively involved in the process by investing staff capacity and resources at different levels: the Leadership Team, the development of a Research Agenda for Zero Leprosy, and the development of a Toolkit for Operational Excellence. This toolkit will, among others, include best practices and innovations developed by NLR.

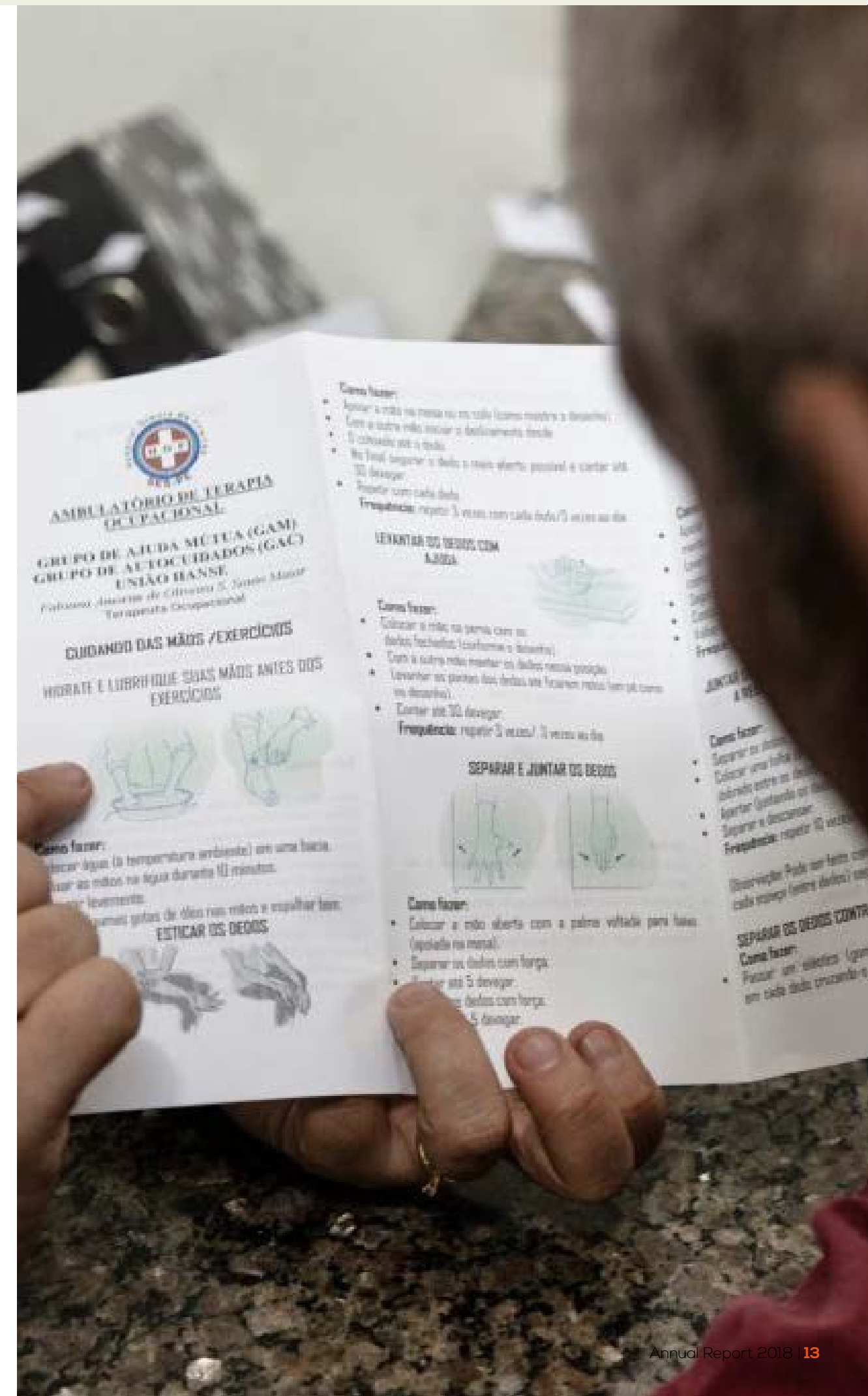
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In 2018, our programme strategy continued to focus on two major innovation processes: decentralising the organisation in accordance with NLR's 2020 process, and developing priority programmes to give more focus to our work.

Again, investments in fundraising paid off. Results were better than expected, both in private and in institutional fundraising.

The income made available again tops our targets in all categories: private donations, legacies, and institutional fundraising. While the implementation of the "Stop the transmission of leprosy!" project, sponsored by the Dutch Postcode Lottery through its "Dream Fund," continued to progress, we also faced delays. Lengthy procedures for ethical clearance upset our plans. In all three countries, significant efforts have been made to prepare for the distribution of the new regimen in 2019. Also in 2019 we will decide on the use of a screening test. To assess reliability, various test options were piloted in 2018.

In June 2018, we celebrated the decision of the World Health Organization to strongly recommend the provision of chemoprophylaxis (single dose rifampicin) to direct contacts of leprosy patients. The organisation did so in its new guidelines for leprosy programmes. The development means that an important innovation, introduced in 2013 by NLR and the Indonesian Ministry of Health in a first pilot district, six years later resulted into World Health Organization adaptation of a new standard for all endemic countries. If applied worldwide, this intervention has the potential to dramatically impact the incidence of leprosy and prevent many at risk of contracting the disease.



2018 evaluated

Furthermore, in 2018 we almost completely phased out funding for our programmes in Nigeria and the Mekong Region. Transition funding will come to a full stop in 2019. NLR's offices in both countries have started procedures to be registered as local NGOs in 2018 (Nigeria and Mekong). We are looking forward to continued collaboration inside NLR's Alliance, enabling the local NGOs to tap into insights acquired and methods developed by NLR.

NLR2020 is the process of transforming our Country Offices into local NGOs. To learn from the progress made thus far, NLR2020 was evaluated halfway through 2018. The mid-term review concluded that though the transformation is well underway, the process of preparing the NLR Alliance as meeting ground for NLR and the locally registered NGOs, must be accelerated. A key priority in acceleration is the engagement of the chairs of local boards in the overall governance of the NLR Alliance. Our decision to reinforce the capacity of programme management and Institutional Fundraising staff materialised when the European and Developing Countries Clinical Trials Partnership (EDCTP) approved of the PEP4LEP project, from a joint call by EDCTP with the Leprosy Research Initiative (LRI). PEP4LEP aims to introduce chemoprophylaxis in three African countries while testing the effectiveness of two different introduction methodologies.

The quality of our operational processes and standards were reaffirmed by the renewal of the ISO certification of the International Office. We also adapted privacy protection policies and procedures, which regulate the use of personal data as stipulated by the European General Data Protection Regulation (Dutch: AVG). By the end of 2018, NLR was fully compliant with the regulation's relevant parts.

In 2018 we were, like many others in and around the international NGO sector, deeply shocked by news reports revealing an integrity crisis in humanitarian work. The news triggered extensive reviews of our principles, codes, procedures, and behaviours designed to maintain our integrity. We shared and discussed these with all staff across all NLR Offices and departments. In 2018, all NLR staff signed and recommitted to our Code of Conduct. We considered this necessary, because we are convinced that we – NLR employees and volunteers – can only fulfil our mission and vision if we do justice to the fundamental principles of humanity, expressed in respect for human integrity and dignity, and can be held accountable for our policies and practices.



2018 evaluated

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. Leprosy Post-Exposure Prophylaxis; 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 neglected tropical diseases.
- 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.
- Low political commitments in many leprosy-endemic countries.
- Sharp decline in technical leprosy capacity worldwide.

Plans for 2019

Looking ahead

Starting from 2016, NLR engages in a number of impactful processes of change. Examples are decentralisation under NLR2020, working with priority programmes, and the implementation of innovative projects to stop the transmission of leprosy. In 2019, we will be looking for opportunities to see our innovations adopted by more national leprosy programmes, as detailed in the Toolkit for Operational Excellence of the Global Partnership for Zero Leprosy.

- Under NLR2020, we are transforming our Country Offices and International Office in the Netherlands into an Alliance of five plus one local NGOs that are well-connected with governments, networks, and organisations of persons affected by leprosy and persons with disabilities.
- Furthermore, we will continue to strengthen programme planning, monitoring, and fundraising skills to increase the overall quality of the work done and improve access to national and international funds.
- In 2019, we will start the actual transfer of assets, responsibilities, staff and contracts to locally registered NLR NGOs. In 2019, besides the Round Table – the proven platform for interaction between the directors of NLR Country Offices and our International Office – we will convene the first meetings of the Council of Chairs. This council is meant to facilitate interaction between the boards of NLR NGOs, represented by their chairpersons. The aim of the council is to promote the joint development of strategies, priorities, and governance within the newly formed NLR Alliance. During its first year of operation in 2019, the council will focus on governance issues and the terms for gradually handing over responsibilities of NLR's Country Offices to locally registered NGOs.
- In the international arena, as an active member of the International Federation of Anti-Leprosy Associations (ILEP) we will continue to participate and invest in the framework of the Triple Zero Campaign and the Global Partnership for Zero Leprosy. In 2019, the Global Partnership will present its research agenda for Zero Leprosy. We aim to align this agenda with the conclusions of the external review of the Leprosy Research Initiative (LRI), which was performed in 2018 after LRI's first five years of operations. Discussions will take place and conclusions will be drawn in 2019.
- With many leprosy experts approaching retirement, we will seek to sustain technical leprosy capacity in all parts of NLR. We will also continue promoting the publication of evidence that has already been obtained through our programmes but was not yet published.
- In our private fundraising in the Netherlands, we will continue investing in future-proofing our fundraising strategy. We will deepen long-lasting partnerships with private donors and experiment with new methods of fundraising. Upgrading our Donor Relations Database will be a major challenge. It is meant to support our ambition to further personalise long-term relationships with private donors and meet their specific requirements and expectations.
- In 2019, we will further invest in and update our ICT and communications infrastructure. We will focus on external communications with donors, other stakeholders, and the public at large, as well as create an effective platform for web-based collaboration, communication, and accountability within the NLR alliance.

“ In 2019, we want our innovative projects adopted by more national leprosy programmes. ”





Driving innovative breakthroughs

Our innovations

In 2018, we celebrated several very important milestones in our pursuit of innovation. A major breakthrough was the official recognition of single dose rifampicin as chemoprophylaxis for leprosy in the leprosy guidelines of the World Health Organization. NLR was actively involved in the research and pilot projects which led to this result. Furthermore, new and promising multi-country projects, such as the PEP4LEP project introducing chemoprophylaxis to Africa, saw the light. The successes obtained in 2018 drive us to continue developing and expanding our innovative work during the years ahead of us.

WHO guidelines for leprosy diagnosis, treatment, and prevention

In 2018, the World Health Organization published its first guidelines on leprosy as part of renewed efforts to eliminate the disease. Previous leprosy guidance documents came in the form of meeting reports and other technical documents, but official guidelines had never been issued. Official guidelines are developed using a thorough evidence-based guideline development method.

The guidelines recommend the use of single dose rifampicin as a preventive treatment for adult and child (two years of age and up) contacts of leprosy patients. The chemoprophylaxis of leprosy (COLEP study, co-funded by NLR, found in 2008), randomised

controlled trial found a single dose of rifampicin in leprosy contacts associated with a 57% reduction in the risk of developing leprosy. Furthermore, single dose rifampicin appears highly cost-effective, and the Leprosy Post-Exposure Prophylaxis (LPEP) programme (2015 - 2018) proved the feasibility of integrating single dose rifampicin distribution into routine leprosy control.

The inclusion of the use of single dose rifampicin in the World Health Organization leprosy guidelines can be seen as a huge success of NLR's single dose rifampicin research and implementation efforts, among which is the LPEP programme.

Stop the transmission of leprosy!



Our “Stop the transmission of Leprosy!” project, funded by the Dutch Postcode Lottery through its “Dream Fund,” saw increasing momentum throughout the year across its three countries of operation: India, Indonesia, and Brazil. By the end of 2018, the national teams had gained more autonomy to push their operational plans and achieved the following outcomes:

- All new leprosy cases identified during the period 2014-2018 were mapped in India and Indonesia, with initial maps being produced in Brazil – a key step in the identification of the highest at-risk areas (clusters) for leprosy transmission. These areas will be targeted in wide-coverage (blanket) campaigns.
- In India and Indonesia, research teams completed the perception studies to understand how local communities perceive leprosy and its stigma. The Indian team then used the results to develop a range of community education/behavioural change materials and methods; Indonesia will begin this step early in the coming year. Brazil has nearly reached completion of the perception study in one municipality. These are all essential steps towards achieving stigma reduction in the various communities.
- The programme is nearing a decision on the reliability of a field-ready screening test that should detect subclinical leprosy infection in contacts. At the end of the year, Brazil’s pilot study was ready to begin collecting the data needed to arrive at a final decision.

In 2019, the first doses of PEP++, a combination of preventive drugs that should lead to an 80-90% reduction of leprosy transmission, will be handed out in all three countries.

Leprosy Post-Exposure Prophylaxis (LPEP) Programme

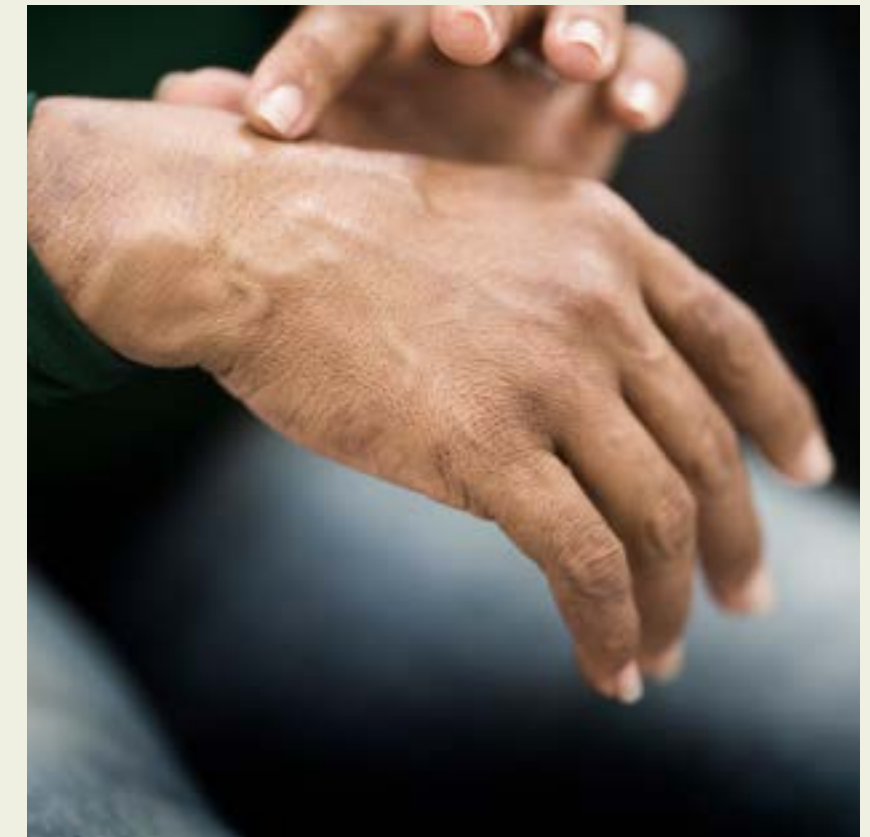


Since its launch in 2015, the Leprosy Post-Exposure Prophylaxis (LPEP) research programme has been implemented in eight countries. The project demonstrates the feasibility of distributing a single dose of the antibiotic rifampicin among contacts of people with leprosy, reducing contacts’ risk of developing the disease. We have been involved in the implementation of the programme in India, Nepal, Indonesia, and Cambodia in close collaboration with these countries’ Ministries of Health. Novartis Foundation coordinates and funds the programme.

In 2018, the data collection phase of the programme was completed in India, Indonesia, and Nepal. In Cambodia, data collection will come to a closure in 2019. The approach has proven to be feasible and well-received by persons affected by leprosy, their contacts, and local health workers. As such, the approach will not only be continued as part of routine leprosy control programmes in the LPEP project areas, but also expand to other endemic areas. In 2018, India fully adopted contact screening and single dose rifampicin distribution as its nationwide approach.

In September 2019, the LPEP programme’s overall results will be presented during the International Leprosy Congress in Manila, the Philippines.

SkinApp



In under-resourced settings, NLR observed a scarcity of health workers with sufficient knowledge of skin diseases. The observation led us to develop the SkinApp: a tool for timely diagnosis and treatment. This smartphone application helps health workers recognise early signs and symptoms of skin diseases – such as leprosy – and provide prompt treatment to prevent disabilities as well as psychological and socio-economic consequences.

In 2018, the third version of the SkinApp was released and a validation process kicked off at Erasmus MC (Rotterdam, the Netherlands) and Bugando MC (Tanzania). The process aims to evaluate the diagnostic accuracy of the SkinApp when used by health workers attending to persons with skin diseases. The validation of the app’s third version is the first step towards rolling out country-specific versions in Indonesia, Brazil, Mozambique, Ethiopia, Tanzania and Nepal, among other countries.

PEP4LEP



PEP4LEP is a research project that compares 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. The dermatological screening process is an evidence-based and World Health Organization-supported method to detect leprosy. NLR's SkinApp will be used as a tool supporting community health workers to diagnose and treat skin diseases. The comparison of the two interventions is made by studying patient detection rates, delays in case detection, cost-effectiveness, the capacity of health workers, and the degree to which stakeholders accept both interventions. The European and Developing Countries Clinical Trials Partnership (EDCTP), the European Union, and the Leprosy Research Initiative (LRI) financially support the project. Consortium partners in this project are: Erasmus MC in the Netherlands, GLRA, German Leprosy and TB Relief Association in Germany, Universidade Lúrio in Mozambique, Armauer Hansen Research Institute (AHRI) in Ethiopia, Bugando Catholic University of Health and Allied Sciences (CUHAS) in Tanzania, and the Ministries of Health in Mozambique, Ethiopia, and Tanzania.

PEP4LEP started in October 2018. The research protocol was finalised and sent to Mozambique, Ethiopia, and Tanzania for translation and submission for ethical approval. The International Scientific Steering Committee and the consortium members' start-up meetings took place in Dar Es Salaam, Tanzania. During these meetings, the full extent of the project was discussed, and changes to the protocol were made based on input from the organisations, knowledge institutes, and governments involved.

LepVax



LepVax, a project initiated by the American Leprosy Missions (ALM), is a leprosy-specific vaccine designed to not only prevent transmission of the bacteria, but also limit nerve damage in those already affected by leprosy. NLR co-funded the phase 1 trials of LepVax. Phase 1 was designed to demonstrate the vaccine's safety and evaluate the immune response to the vaccine: a critical first step in testing LepVax for clinical use.

The outcomes of the study showed that the vaccine was extremely safe and produced no serious adverse events. The United States Food and Drug Administration (FDA) recommended that the LepVax candidate proceeds to the next phase of clinical trials. Furthermore, the vaccine elicited strong immune responses, peaking after the third injection. This is a positive indication that LepVax will function as designed – boosting the body's natural immune response to the leprosy bacteria.

The next step in the development of the LepVax vaccine is to determine its safety and preliminary effectiveness in people living in a leprosy-endemic area. To this end, a trial is expected to start in July 2019 and will be conducted for two years.



Sharing our knowledge & experience

Infolep & InfoNTD

Infolep is the international knowledge centre for information on leprosy and leprosy-related subjects. In 2018, Infolep attracted more than 20,000 unique visitors across 185 countries. The portal offers access to over 28,500 publications, with more than 1,000 publications added in 2018.

InfoNTD, the portal that was set up based on the success of Infolep, provides information on cross-cutting issues in neglected tropical diseases. During 2018, its second full year, InfoNTD attracted an impressive 15,000 unique visitors, compounding a 50% increase compared to 2017. In 2018, two additional topics were added: Snakebite envenoming and Mycetoma. User survey respondents indicate they benefit significantly from InfoNTD and are keen to recommend it among colleagues.

Both portals offer support, such as library services, upon request: full texts of published articles, grey literature, and assistance with literature searches. The portals also feature tools for fieldwork, such as questionnaires.

Both Infolep and InfoNTD are supported by partner organisations. In 2019, user surveys will be carried out to further improve the services offered.



The Infolep portal attracted more than **20,000** unique visitors across **185** countries



The Infolep portal gives access to **28,500** publications



The InfoNTD portal attracted **15,000** unique visitors

Working together

Priority Programme on Stigma and Mental Well-being

In 2018, we kick-started the development of our priority programme on stigma, discrimination, and mental well-being together with NLR and external partners, such as KNCV Tuberculosefonds, Lepra UK, TLM EW (The Leprosy Mission England and Wales), and The Carter Center Liberia. Together, these partners host a wealth of knowledge and expertise. By means of exchanging experiences, tools, and ideas, we defined common interests and opportunities.

To move forward as NLR, a follow-up workshop is planned for March 2019 to analyse the ways that stigma and mental well-being have already been integrated in our projects.

Temporary Expert Group on Stigma, Discrimination, and Mental Well-being

In 2011, the International Federation of Anti-Leprosy Associations (ILEP) published its guidelines on the reduction of stigma: a series of booklets with tools for assessment of and interventions against stigma. NLR took the lead in the process of writing and producing these guidelines, leading a Temporary Expert Group of ILEP's Technical Commission, with contributions from many ILEP members, scientists, and persons affected by leprosy.

By 2018, substantial additional knowledge and experience had been gained regarding stigma measurement and interventions, including the need to address the mental health consequences of stigma. A revision of the guidelines was started in November 2018 at a first meeting. Given the growing interest in mental well-being and stigma in the field of neglected tropical diseases, the new booklets will focus on Stigma, Discrimination, and Mental Well-being to revise existing guidelines. Again, NLR leads the Temporary Expert Group, closely collaborating with the ILEP Panel of Persons Affected. Four Module teams will revise the guidelines and add new content, especially on mental well-being. The next face-to-face meeting will be held in April 2019.

Writeshop

In December 2018, our International Office's Technical Department organised a five-day "writeshop" in New Delhi, India, together with participants from NLR Country Offices and partner organisations. The writeshop helped participants write up project results, innovations, and research findings in publishable manuscripts – so that our work can be shared and others can benefit from our experiences and findings.

Topics varied widely and included immunology, health systems strengthening, leprosy control, prevention of disabilities, and disease management and inclusion. The first publications are expected in 2019.

Our worldwide work

In 2018, NLR was active in Mozambique, India, Indonesia, Nepal, and Brazil. We almost completely phased out funding of our programmes in Nigeria and the Mekong Region.

Each country is unique, and each individual issue requires special attention. Our approach, therefore, is always tailored to the specific circumstances and needs of the national context. In one country we may focus on the identification and treatment of leprosy, whereas another country may require support around disability and inclusion. The largest numbers of new leprosy cases were identified in our programme areas in India, Brazil, and Indonesia.

Brazil

1,679

new leprosy cases*
Realisation: €265,345
Number of employees: 7

[Read more](#)

Phasing out
our work in

Nigeria

Realisation: €155,446
Number of employees: 14

[Read more](#)

Mozambique

486

new leprosy cases*
Realisation: €498,353
Number of employees: 12

[Read more](#)

India

32,024

new leprosy cases*
Realisation: €445,148
Number of employees: 80

[Read more](#)

Phasing out
our work in the

Mekong region

Realisation: €723,856
Number of employees: 5

[Read more](#)

Nepal

852

new leprosy cases*
Realisation: €292,033
Number of employees: 18

[Read more](#)

Indonesia

13,135

new leprosy cases*
Realisation: €931,260
Number of employees: 50

[Read more](#)

*New leprosy cases were found, diagnosed, and treated in our programme areas



Mozambique

In 2018, NLR Mozambique worked in sixteen endemic districts in three provinces. Through active case finding activities and improved data collection in collaboration with governmental and other leprosy organisations, we observed an alarming increase in the number of new cases. Thankfully we were able to obtain additional funds from external donors, which paved the way for three new projects starting in our programme area in 2018.

Our results

What did we achieve in Mozambique?

Realisation: €498,353
Number of employees: 12



486

new leprosy cases were found, diagnosed, and treated in our programme areas



69

existing self-care groups (formed before 2018) and 24 newly formed self-care groups were supported



335

health workers, community volunteers and government health staff were trained on leprosy



2,179

persons disabled by leprosy and other diseases were trained in self-care to help prevent (the worsening of) disabilities



94

lives improved with reconstructive surgery



3,417

people were informed and educated about leprosy to raise awareness



415

people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



8,011

community members were informed and educated on general disabilities to raise awareness



3

Disabled People's Organisations received assistance to promote participation of people with leprosy-related disabilities



107

people received a microcredit to help them become self-employed



189

persons with disabilities were helped to stand up for their rights



622

people were provided with leadership training to guide and support others and groups



Story from the field

“I am so relieved that I was diagnosed at an early stage”



Munatiquina is married and has a son with an intellectual disability. “Two years ago, suddenly my body got covered in white patches. I was at my wit’s end. What to do? The community volunteer suspected leprosy and had me examined. Fortunately, we discovered it in time.”

The volunteer’s suspicions were correct: Munatiquina was infected with leprosy. “I have been very lucky, the doctor said. I could have developed deformities, but thankfully I was spared. I am so relieved that I was diagnosed at an early stage. When I heard the news, I immediately thought: ‘Oh, I hope I did not infect my husband.’ By a miracle, I had not. I was not worried about my son. He does not live with us, so he did not run any risk.”

Learning to take care

Munatiquina started treatment right away. Today, one year later, she has almost completed her treatment. “I just started my last medication strip. Recently, I also started attending the monthly self-care group meetings. Here, I learn how to

take care of myself. I wash my hands and feet regularly and thoroughly.

I feel so much better now. However, I am old and have rheumatic knees. My troubled knees make walking difficult. Fortunately, I get pain relief medication and I recently received a pair of crutches, which aids walking. Sometimes I go to the market again and I can visit my son, who lives nearby. The crutches are a big help for my husband as well. He has problems with his spine and has a stoop.

My husband and I grow cassava on our lot and run the home together. My diagnosis with leprosy did not change our relationship. In fact, my husband supports and helps me. He gets water from the river and wood for the fire, for instance.”

Priority programme

Stop transmission of leprosy

Results in 2018

NLR Mozambique's interventions were carried out in sixteen districts (six in Zambezia, four in Niassa, and six in Nampula province).

- NLR provided technical support to more than 100 health professionals on active case finding, which included capacity building in early diagnosis of leprosy and the use of the SkinApp as an auxiliary resource.
- NLR trained 134 community leaders, traditional healers, health volunteers, and staff of Disabled People's Organisations on sensitisation methods and the identification and reference of leprosy. Externally funded projects under priority programmes "Combined approaches to prevention and management of disability" and "Disability-inclusive development" also took up a training component in their activities, at times in combination with a focus on lymphatic filariasis and konzo.
- NLR launched PEP4LEP in three districts of Nampula province. The project is funded by the European and Developing Countries Clinical Trials Partnership (EDCTP) and the Leprosy Research Initiative (LRI). It introduces chemoprophylaxis for leprosy treatment while comparing two different intervention strategies. NLR Mozambique executes PEP4LEP in collaboration with the Ministry of Health and Lúrio University.

Lessons learned in 2018

- The availability of medication is limited and insufficient to cover all newly detected cases. To resolve this issue and make more resources available for leprosy, together with other members of the International Federation of Anti-Leprosy Associations (ILEP), NLR began lobbying the government.
- NLR's training of health district officers prompted their follow-up with capacity building among community health workers and community authorities (leaders, volunteers, and traditional healers) on basic case detection. This successfully increased detection rates.

Plans for 2019

- We will work with the provincial health directorates of Nampula, Zambezia, and Niassa to strengthen active case finding and better drugs supply. This includes contact listing, documentation of leprosy, konzo, and lymphatic filariasis, and trials to identify more effective preventive and curative approaches.
- We will organise training workshops for nurses and district health practitioners teaching them how to diagnose and treat leprosy and konzo.
- We will promote the use of the SkinApp at healthcare units.
- We will collaborate with the media to disseminate messages that sensitise and mobilise the public and help prevent both leprosy and konzo.
- We will implement the PEP4LEP project.



Antonio's community appointed him as a community volunteer. The community considers him a trustworthy man who demonstrated his willingness to help the villagers.

“I work with the local health team, referring people to the hospital when they show signs of leprosy. NLR trained me on leprosy both in 2015 and 2017, and in 2018 I participated in a refresher course. The courses taught me how to recognise the symptoms of leprosy beyond doubt. I am very happy with the techniques I learned: today I feel prepared to help. The training experiences were very important to me. I can make my community healthier and we cultivate the spirit of mutual support.”

Highlighted project

PEP4LEP

From the total number of new cases in 2018, 39 were children and 84 had deformities at the moment of examination. The incidence increase is attributed to a higher-quality online governmental patient registration system, which was improved by ILEP member The Leprosy Mission Mozambique. Another potential reason is a small increase in active case finding activities.

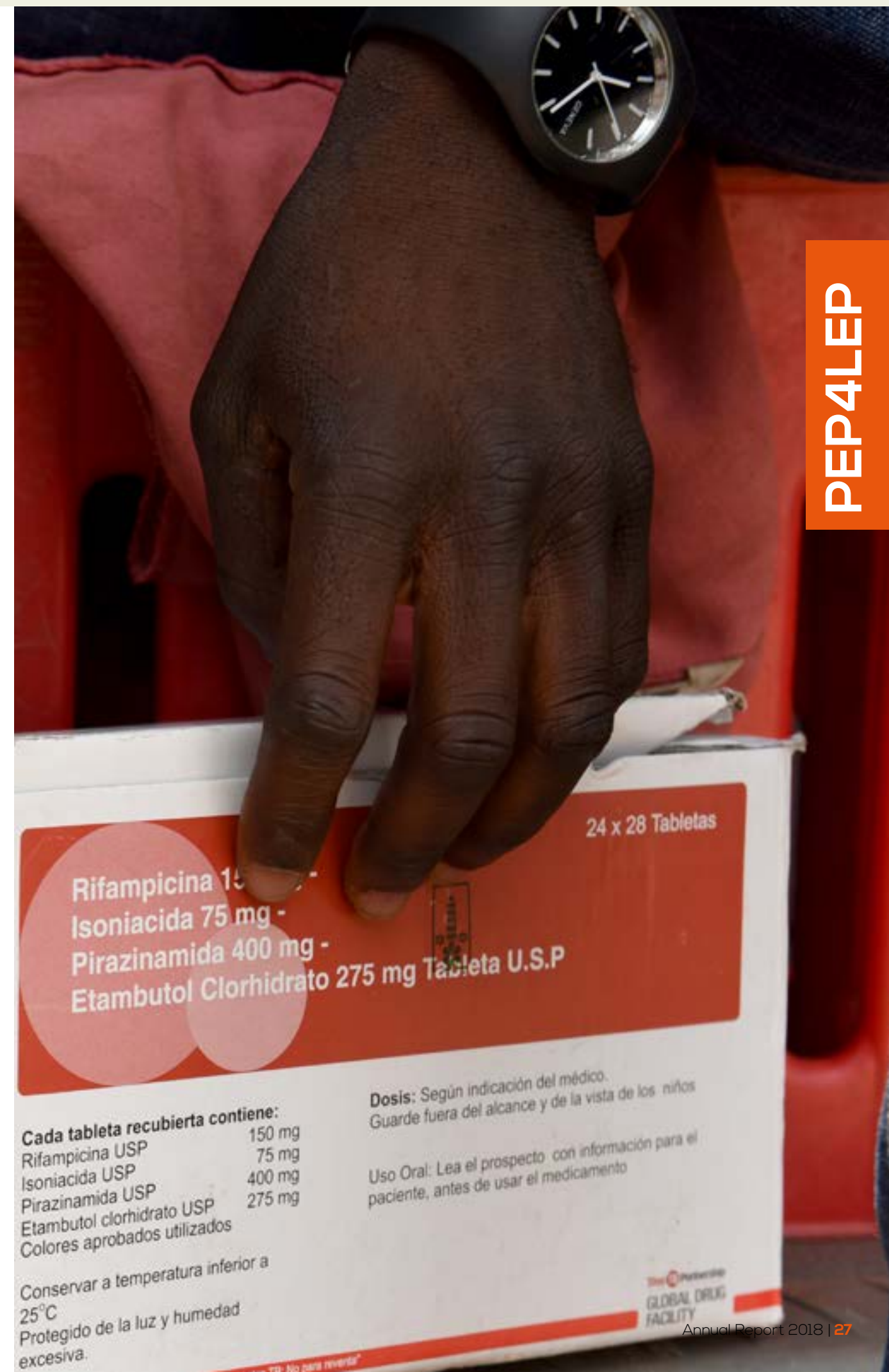
The recently started PEP4LEP project aims to contribute to a reduction in the transmission of leprosy in Mozambique. A new leprosy screening approach will be tested and contacts of leprosy patients will receive the preventive antibiotic rifampicin. PEP4LEP will take place in three districts (Murrupula, Mekonta and Mogovolas) in Nampula province, as this is the province with the highest number of leprosy patients in Mozambique.

Lessons learned in 2018

A 2018 field visit found that multiple districts in Mozambique have shortages of the multi-drug therapy. Consequently, the treatment of many patients started with delays.

Plans for 2019

Collaboration with other ILEP partners and the Ministry of Health seeks to solve the multi-drug therapy shortages. Ethical approval for PEP4LEP is expected to come through in the first semester of 2019, while validation of the SkinApp and the case detection delay protocol will be performed during the first half of 2019. Subsequently, local health staff will be trained and in the second half of 2019, the inclusion of index cases and contacts will commence. NLR is aiming to collaborate with the Ministry of Health and The Leprosy Mission Mozambique to further improve the functionality of the DHIS2 patient registration system.



PEP4LEP



Priority programme

Combined approaches to prevention and management of disability

In 2018, NLR's planning did not include this priority programme in Mozambique. However, two specific projects, funded by the government of Australia through its Direct Aid Programme (DAP) and by Lepra UK, contributed to results obtained in this field. Moreover, the project "Disability Inclusive Agriculture and Health Development" contains a component of support to combined self-care and self-help groups.

In 2018, we learned that the lack of reliable data at the Ministry of Health hampers effective planning and budgeting. NLR successfully obtained funds from the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD) to start a project in two

districts in Nampula province. This project introduces a combined mapping on the delivery of/access to Morbidity Management and Disability Prevention for persons affected by leprosy, lymphatic filariasis, and konzo, and will start early 2019.



Highlighted project

Improving disability prevention and contributing to disability reduction

In 2018, we ended a three-year project on combined approaches with funds from Lepra UK. This project addressed the needs of persons affected by and at risk of lymphatic filariasis and leprosy in Zambezia province. An evaluation study was carried out to document the project's learnings.

Results in 2018

- The project made a significant difference for 2,025 persons affected by lymphatic filariasis and leprosy as well as their 8,090 family members. The project enabled affected persons to lead healthier and less dependent lives through an integrated approach tackling health issues, obstacles to income generation, and stigma associated with leprosy, lymphatic filariasis, and other disabilities.
- Significant changes occurred in four domains: access to disability services; skills and capacity of the public health services and Community-Based Organisations to appropriately address health issues; social and economic needs of affected people; socio-economic status of people affected by disability and the number of lymphatic filariasis- and leprosy-affected people seeking treatment and claiming their rights.
- During the project period, we supported 63 self-care groups that together hosted 1,296 members (815 men and 481 women). We trained 180 community health volunteers, 660 teachers in 68 schools, and 111 community leaders. In the four districts, we trained and coached community health workers.

Lessons learned in 2018

- A combined approach is very appropriate in poor rural areas with limited access to healthcare services. Not limited to a single disease, a combined approach creates opportunities to provide several services at the same time.
- The decision to combine those affected by lymphatic filariasis and leprosy in the same self-care groups was received very positively, especially by members themselves.

However,

- Consolidation requires continuation and/or follow-up.
- Although the project put specific emphasis on female participation, a more thorough gender analysis is required.

The main lessons and recommendations were shared during a workshop attended by all NLR Country Offices and other members of the International Federation of Anti-Leprosy Associations (ILEP). The project is considered a success and the approach serves as a model for replication, in Mozambique and in other countries.



Highlighted project

Strengthening prevention and community-based rehabilitation for people affected by konzo and leprosy disabilities in Zambezia province

In 2018, funds from Direct Aid Pretoria (DAP) enabled us to implement a combined approach to leprosy, konzo, and other disabling diseases in four districts in Zambezia province. By means of sensitisation, detection, and support for self-care groups, the project aimed to:

- Increase early detection rates for konzo and leprosy through active searches performed by inclusive self-care groups and teachers.
- Meet the rehabilitation needs of people with disabilities in the target area.
- Sensitise communities and government agencies on the prevention of konzo.
- Improve diets by introducing healthier methods of processing cassava and other locally grown crops.
- integrated self-care groups, and 20 healthcare staff directly benefited from this project.
- Sensitisation campaigns on bitter cassava processing methods reached 7,907 people. For this purpose, specific Information, Education, and Communication materials were produced.
- Community Rehabilitation Centres were set up and are used by the integrated self-care groups. Here, 415 assistive devices were produced and distributed.
- Improved capacity of health services to monitor, prevent, and treat konzo and leprosy.
- With the help of video materials, the Health Department in Zambezia and Nampula provinces have been sensitised to konzo.
- A need for the provincial government to include konzo in their planning as a priority disease.
- The ministry of health lacks credible data, which hampers effective planning for prevention.

Results in 2018

- Government staff (20 health workers), members of self-care groups, and community leaders trained on the diagnosis of leprosy and konzo, cassava processing practices, and Community-Based Rehabilitation. Training sessions also targeted Disabled People's Organisations and teachers.
- A total of 169 people affected by konzo (plus 289 in 2017), 131 by leprosy, 95 by lymphatic filariasis, 47 by other disabilities, 23 schools, 2 Disabled People's Organisations, 20

Lessons learned in 2018

- 458 people in the project suffered from a disability caused by leprosy or konzo. This indicates the majority of cases is detected too late.

Plans for 2019

- With DAP funds, a new project will implement the lessons learned in 2018. The project will consolidate the capacity building of district health personnel, teachers, and community health workers.
- A new focus in 2019 will be the lobby for the inclusion of leprosy, konzo, and other disabling neglected tropical diseases in the annual plans of the Ministry of Health. Equal efforts will be invested in lobbying for a consolidated approach to address all neglected tropical diseases in the country, and an updated, accurate database at the ministerial level.



Story from the field

“Now we know how to remove the toxins from cassava”



From one day to the next, both Andolino and his younger sister Esmeralda became paralysed. Their parents were desperate. How could this have happened? That cassava was to blame, would never have occurred to them.

“My wife Lucia and I took our children to the local health centre,” says father Janvahio. “We wanted to find out what had caused the paralysis in the lower part of their bodies. Unfortunately, the doctor could not help us and referred us to the district hospital. In the end, we never went. Not because we did not want to, but because it is too far to walk and we did not have enough money to pay the bus fare. We were on our own, and did not get any help.”

our children now suffer from the crippling disease konzo. Sadly, konzo cannot be treated. Prevention is the only option. A special course taught us various methods of removing the toxin from the crop’s roots and leaves. We now follow these methods. Unfortunately, however, Andolino and Esmeralda will never regain their health. Their paralysis cannot be undone.”

Poisonous cassava

“Eventually, we discovered our children became permanently paralysed from eating insufficiently detoxified, bitter cassava. The crop released too much hydrocyanic acid into their system. Our simple diet is made up of cassava most of the times. We ate both the roots and the leaves. If only we would have known the importance of detoxifying cassava. Because we did not properly prepare our food,

Rehabilitation

“I realise only too well that our son will never walk again. I am very grateful that he received a wheelchair. It makes us much more mobile. I still have hopes for my daughter though: I think that with an intensive rehabilitation programme she will learn how to walk again. In fact, it is my biggest wish. If she can walk, she can go to school.”

Priority programme

Disability-inclusive development

Results IN 2018

In Nampula, NLR worked with the Associação dos Deficientes Moçambicanos (ADEMO), a local Disabled People's Organisation that is active in three districts.

- ADEMO was trained to implement a participatory baseline study as an initial step towards a disability-inclusive community. The study's results indicate a lack of government services and awareness on the needs and rights of affected persons among public servants.
- Activities were set up to help self-help group members generate income. A total of 107 people (76 women and 31 men) are now participating in saving schemes. 30 people (19 men and 11 women) received cattle, while 23 women were trained and received support to set up a small business.
- ADEMO members and district government staff in the health, women, and social action departments were trained in data collection, analysis, and results-based management. ADEMO aims to participate in and influence the Community-Based Rehabilitation Committee, a decision-making institution at the district level.

Lessons learned in 2018

- Involving the local Disabled People's Organisation is key. ADEMO proved to be an important actor and NLR will continue to use ADEMO's specific knowledge and experience in Nampula to increase the effectiveness of its work among self-help groups in Zambezia.
- Existing self-care groups were used as entry point for ADEMO's work on inclusiveness in communities. At times, self-care groups need to be reactivated with the support of district health staff.
- It is not a given that Disabled People's Organisations like ADEMO possess the knowledge and skills required to work with leprosy-affected persons. Therefore, specific training on leprosy and working with self-care groups was organised for all ADEMO members.
- No disaggregated data is available on disability, which hampers government planning.

Plans for 2019

- We will establish a disability-inclusive community in Nampula as a model to be replicated in other provinces in 2020.
- We will promote socio-economic rehabilitation by helping self-care groups establish income generation activities.
- We will continue executing an externally funded project on Inclusive Agriculture and Health in two districts in Zambezia.





Story from the field

“My small business improves my living standards”



During treatment, Atia became a member of a self-care group in her village. She was not only trained in self-care, but also financially supported to set up a small business in pea beans. With the money she earns, Atia can now buy school materials and uniforms for her three children. She is even planning to participate in adult literacy classes in the near future.

“For a long time, I had a patch on my arm without knowing what it was. Then I started feeling pain and a burning sensation. I tried to treat traditionally for a year and eight months, but unsuccessfully. In 2017, ADEMO activists visited my village. They invited the community to a meeting about skin diseases and I decided to participate. A nurse from the local hospital spoke about leprosy. After her talk, she invited us for a screening.”

Small business owner

“That day I was diagnosed with leprosy and started treatment. The president of the self-care group, Mr Paulo, invited me to become a member. I was explained how the group functions and I decided to join. I was trained in self-care, and for eighteen months and I practised at the group. Today I feel better, but sometimes I have eye problems.

In 2018, we were explained how we could work together and help each other. ADEMO introduced loans and trained us on small business management. I received 1,000 Mozambican meticals (approx euro 14) and invested in a pea beans business. During the season, I earn 500 meticals (approx euro 7) per month.”

School fees

“With the income I earn, I joined the saving group and our group was upgraded from self-care to inclusive self-help group. I can now buy school materials and uniforms for my children.

I am very happy: my life is improving. In the near future, I even plan to participate in adult literacy classes. With the income from my business, I consider expanding my farming plot so I can produce more, sell part of the harvest, and buy plastic chairs, mattresses, and zinc sheets to cover my house.”



Highlighted project

Disability-inclusive agricultural and health development in Zambezia province

This two-year project aims to improve the food security and nutritional status of 1,000 smallholder farmers and their families living across two districts, as well as achieve social inclusion for community members living with leprosy, lymphatic filariasis, konzo, and other disabilities.

Results in 2018

- A comprehensive baseline study was performed to facilitate future project implementation and monitoring.
- We rolled out training sessions on agricultural conservation techniques attended by 1,180 participants. 711 attendees are persons affected by leprosy, lymphatic filariasis, konzo, and other neglected tropical diseases. These techniques do not only sustain and boost production, but also take a significant part of the effort out of farming, which makes a tangible difference to people living with a disability.
- In order to transition self-help groups into fifty small farmers' organisations, their members received training on business management, organisational governance, leadership, and conflict management.
- Sixteen task forces, composed of community members, were created and trained to advocate for the rights of persons affected by leprosy and other disabling diseases. We sensitised government staff to the rights of affected persons, and helped them better execute their duties and obligations in service

delivery to affected persons.

- Community health workers, local leaders, and volunteers were trained on early detection.
- Community rehabilitation hubs were built to provide community-based rehabilitation and take health services much closer to remote communities.

traditional norms and cultural values. Change begs long-term and strenuous effort.

- To increase the commitment of local authorities – needed to successfully implement local projects – their continued involvement is vital.

Lessons learned in 2018

- Every partner brings their own, unique expertise to the table. It is crucial that project partners understand each other's work and roles. A specific training session was organised to harmonise and clarify the cross-component indicators (health and agriculture) for the field officers involved.
- Often leaders of local organisations (including self-care groups) are not selected on the basis of their leadership skills, but on their influence and power in communities. To avoid conflicts in a transition from self-care groups to farmer's organisations, current leadership will be maintained. However, leaders will be trained to ensure democratically led groups.
- Discussing human rights, gender issues, and the disability dimension touches directly on

Plans for 2019

- We are planning a field staff exchange visit to a similar project in Bangladesh.
- We will continue and consolidate agricultural and nutritional training.
- We will continue to invest in the relationship with governmental agricultural services and strengthen farmers' organisations so they can deliver quality services to their members.
- We pursue increased disability prevention and reduction through early case detection and group physical rehabilitation.



India

Leprosy enjoys high political commitment in India, at least at the national level. NLR has been working closely with government staff to strengthen their capacity through monitoring and supervision. This ultimately improves the quality of services in the leprosy and disability sector.

Our results

What did we achieve in India?

Realisation: **€445,148**
Number of employees: **80**



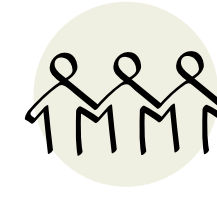
32,024 new leprosy cases were found, diagnosed, and treated across our programme areas



7,882 direct contacts of new leprosy patients were given a single dose of rifampicin to reduce their risk of developing leprosy by 50-60%



2,317 health workers, government health staff, community volunteers and accredited social health activists (ASHAs) were trained on leprosy



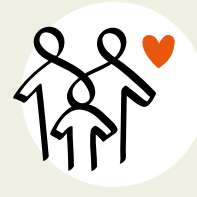
2,000,000 people were informed and educated on leprosy to raise awareness



178 people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



22 community members were informed and educated about general disabilities to raise awareness



571 existing self-care groups (formed before 2018) and **6** newly formed self-care groups were supported



242 persons disabled by leprosy and other diseases were trained in self-care to help prevent (the worsening of) disabilities



7 lives were improved with reconstructive surgery



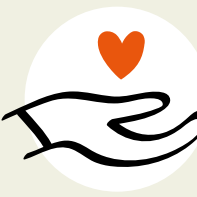
16 Disabled People's Organisations received assistance to promote participation of people with leprosy-related disabilities



44 people were provided with leadership training to guide and support others and groups



185 people received vocational training to learn a trade



967 children of leprosy-affected persons received financial support for their education



8 people received a microcredit to help them become self-employed



45 persons with disabilities were helped to stand up for their rights



Story from the field

"This is my new family"



Laxmi was only a young girl when she got leprosy. No one looked after her. She got scoffed, spit at, and sent away. Even by her own family. She found her way to a leprosy colony in Agra where she did find love and acceptance. Together with the other residents, she is working towards a hopeful future at the colony.

"I got leprosy when I was twelve years old. My entire body was covered in white spots, and my fingers became disfigured. Despite the symptoms, I did not seek treatment. I got married when I was eighteen. When my husband discovered I had leprosy, he abandoned me. I went back to my parents, but they too discriminated against me. I had nowhere to go. No one wanted me. It was excruciating."

Encouragement

"One day I met a lady I will never forget. She too had leprosy and said: 'I'm just like you. Keep your hopes up. Your hands might never recover, but your pain will be alleviated.' Her soothing words encouraged me to visit the hospital for treatment."

After a few months, the doctor said I was healed, and wanted to dismiss me from the hospital. But I was not ready at all! I did not want to go back home. I would have endured the same countless insults. I

lost my spirit and considered to end my life. My body was deformed, but so was my soul of sadness."

Love and acceptance

"Thankfully, the lady who helped me earlier told me about a leprosy colony in Agra, where I decided to go. I was 26 at that point. Society loathed me, but at the colony I found love and acceptance. I felt welcomed right from the start. We take care of each other in good and in bad times. We see each other as a new family. I got remarried, and I now live here with my son, my daughter-in-law, and my grandson."

I want to forget my past. And work towards a hopeful future here at the leprosy colony. It is my fate, and this has become my new family. Every day I visit the temple to pray. I pray that my biggest wish, to receive new hands and feet, may come true. Because I am so eager to help others."

Priority programme

Stop transmission of leprosy

Results in 2018

NLR supported the National Leprosy Eradication Programme of India at the national level, in 120 districts, and across seven states, in Northern India. Through technical support, lobbying, and advocacy, new initiatives have been taken up by the Central Leprosy Division. The Leprosy Case Detection Campaign led to early detection of 16,125 cases in five NLR-supported states and a reduction in cases with grade 2 disability down from 4.6% in 2017 to 3.8% in 2018. Various innovative concepts, introduced by NLR, were well received by the National Leprosy Eradication Programme. Chemoprophylaxis using a single dose of rifampicin is now national policy, mathematical modelling is likely to be introduced under the National Leprosy Eradication Programme, and the use of Geographic Information Systems has kicked off case mapping.

Lessons learned in 2018

To influence government adaptation of innovative approaches, evidence generation is key. Involvement of community representatives and female health volunteers improves early case detection and decreases the number of disabilities.

Plans for 2019

In 2019, NLR India would like to see the healthcare system providing quality services in NLR-supported states. This should lead to a further reduction of the New Case Detection Rate (NCDR), including a reduction in child proportion and grade 2 disabilities among new cases. NLR India would like to see the introduction of PEP throughout the country, with a good quality and coverage of SDR-PEP in at least 55 NLR supported districts. NLR will promote early case detection in hard-to-reach areas and a correct implementation of chemoprophylaxis.



Highlighted project

Stop the transmission of leprosy!

Results in 2018

- India completed the full cycle of a perception study and the development of community education/behavioural change materials and methods. These are essential steps in preparing communities for the full implementation of the interventions and stigma reduction measures.
- India's research team successfully mapped the GPS coordinates of all index patients detected between 2014 and 2018, leading to the definition of the highest at-risk clusters for leprosy transmission.

Lessons learned in 2018

- Since India completed parts of the project ahead of other countries, the team began approaching index patients for a full listing of their closest contacts (their household, family members, neighbours, and their social network). From this research, we identified several difficulties and limitations. Understanding these will aid the full implementation of the intervention. Moreover, we now have a better idea of the average number of contacts.

Plans for 2019

- In the first quarter of 2019, we will finalise the best-updated maps and carry out the block randomisation of control/intervention areas. Next, the local team will carry out a trial ahead of the full intervention (time/motion study).
- During the first semester of 2019, India will be the first country to conduct the blanket campaign and distribute the new chemoprophylactic regimen.



Highlighted project

LPEP

Results in 2018

India was the first country to round up data collection for the LPEP project. In total, more than 30,000 contacts received single-dose rifampicin, of which more than 13,000 were children between the ages of two and fifteen. Main stakeholders were very receptive to contact screening and single-dose rifampicin administration, as was shown by a sub-study into acceptability.

Lessons learned in 2018

Data collection was labour-intensive. Health workers nevertheless reported being motivated by the fact that they could offer communities a preventive measure. A decrease in the annual number of new cases diagnosed, from 425 in 2015 down to 273 in 2018, is very encouraging.

Plans for 2019

The LPEP project activities were embedded in the routine leprosy control programme and will continue as such now that the project has officially ended. The national leprosy control programme incorporated the LPEP approach into its national guidelines, together with a simplified data collection component. A dissemination meeting is planned with state leprosy officers from other endemic areas to share the project's results and experiences.



Priority programme

Combined approaches to prevention and management of disability

Results in 2018

Six combined self-care projects were started in 2018. 242 persons joined: 160 with leprosy, 80 with lymphatic filariasis, and two suffering from diabetes. Out of 67 patients with leprosy-caused planter ulcers, 47 were healed (70.1%) and 72 out of 80 (90%) lymphatic filariasis cases have shown reduced swelling. NLR India also involved General Health Care (GHC) staff, training them to perform self-care practices and follow-up. In total, 220 GHC staff were trained to make the intervention sustainable. 1,200 volunteers (ASHAs) were trained to follow up self-care practice at home.

Lessons learned in 2018

Combined training in self-care of people affected by leprosy and lymphatic filariasis is possible, useful, and resource-effective. Nothing stood in the way of the two groups learning and practising self-care together.

Plans for 2019

In 2019, we will continue to train persons with disabilities caused by leprosy and lymphatic filariasis. Our activities should lead to reduced swelling among 90% of lymphatic filariasis cases with grade 1 and grade 2 disabilities, and healing of 80% of leprosy ulcers. In 2019, we expect to train 180 disabled people on self-care.



Because Iswari got leprosy, deformities appeared on this right foot.

“The ulcer on the sole of my foot started to worry me. Shortly after, NLR started a self-care camp at the Barhi Community Health Centre. I joined the camp and started practising self-care under the guidance of the instructors. They taught me how to take care of my ulcers on a daily basis. As a result, my ulcer got healed and new ulcers are prevented. I am now completely free of ulcers. I have witnessed the same positive results among peer groups.”

Priority programme

Disability-inclusive development

Results in 2018

NLR empowered persons with disabilities – including those affected by leprosy – to stand up for their rights. In total, 204 self-help groups, including 435 persons affected by leprosy, 11 Block Development Committees, and 11 Disabled People's Organisations have been established in Aurangabad district of Bihar. Members come from a total of 3,780 families. 768 people (52 youths from leprosy-affected families and 716 with general disabilities) received vocational training. 967 children of persons affected by leprosy received educational support.

Lessons learned in 2018

The self-help groups, Block Development Committees, and Disabled People's Organisations played an important role in advancing disability-inclusive advocacy. 575 families established their own livelihood with the support of the self-help groups, which hold a collective savings fund of INR (India Rupee) 3,271,749. To prop up self-help group efforts, financial institutions now come forward with loans for self-employment and micro-enterprises.

Plans for 2019

In 2019, we will strengthen existing groups and establish one hundred new groups to cater to the needs of disabled people. We will also enhance the socio-economic status of affected persons by focusing on skill development, livelihood promotion, inclusion, and accessibility.





Story from the field

“Running my own shop set me back on my feet again”



With a loan he obtained through one of our self-help groups, Sujit started a small shop. The income he generates today does not only benefit him, but his entire family. With community members gladly stopping by for tea and snacks, social interaction at the store greatly reduced stigmatisation and discrimination of community members living with leprosy.

“I live together with my wife and our three children. Two of them study, one is not yet old enough to attend school. Because I was diagnosed with leprosy too late and did not start treatment in time, I developed deformities in both of my hands. Yet, despite my illness, I have a strong desire to earn my own money and support my family. I do not want to depend on the mercies of others.”

Self-supporting

“NLR encouraged my community to form a self-help group for persons with disabilities, including persons affected by leprosy. I cannot thank NLR enough for what they have done. The group considered my need and provided me with a loan. This enabled me to set up a small shop with cosmetics and children’s items. I make a small daily income and am now fully self-supporting.”

Transformed community

“Over time, my wife started a snack shop adjacent to mine. We are committed to working hard for our money, which sends a strong message to our community. Villagers gladly stop by for tea and snacks served by my wife and me. The social interaction we have with our customers greatly reduced stigmatisation and discrimination of community members living with leprosy.

Running my own shop set me back on my feet again. It gives me back my dignity. I also would not know where to begin thanking NLR for its support of my two children. They both participate in NLR’s education programme. With NLR’s help, my family and I can now build a brighter, better future.”

Priority programme

Reduction of stigma and discrimination

Results in 2018

NLR played a major role in the government-run stigma reduction “SPARSH” campaign. The campaign was organised in six NLR-supported states; it featured rallies, meetings at different levels, and oaths taken by communities and their leaders not to discriminate against persons affected by leprosy, among others. NLR India developed and disseminated video clips on leprosy detection and treatment (called LepClips) and designed and distributed posters to states and districts for production in local languages. District magistrates and Disability Commissioners were sensitised to the needs of disabled people.

During 2018, NLR India supported a total of 768 persons by means of vocational training. NLR supported 52 youths from leprosy-affected families by offering vocational courses ranging from medical laboratory assistant to cargo management and from electrician to motor mechanic. From the group affected by general disability, a total of 716 persons received vocational training. 967 children of persons affected by leprosy received support in their education, which includes participation in professional courses. Educational support plays a crucial role: it shapes the future of the second generation of leprosy-affected families.

Lessons learned in 2018

Stigma reduction messages were spread by campaigns and integrated in other projects. For more conscious integration across all projects, in 2019 we will promote the available tools for stigma reduction and supervise their introduction.

Plans for 2019

For stigma removal, technical support to the National Leprosy Eradication Programme in Information, Education, and Communication activities and the “SPARSH” campaign, will be further strengthened. Counselling meetings will be organised among communities. In cooperation with the International Federation of Anti-Leprosy Associations (ILEP) and other partners, lobby work will be done to amend one more discriminatory law, preferably related to segregation/separation, employment, or voting.





Indonesia

In Indonesia, the start of 2018 was marked by the lengthy process to extend the Memorandum of Understanding between Indonesia's NLR and the Ministry of Health. While waiting, we were not allowed to carry out part of our activities. A new Memorandum of Understanding was signed in July 2018, which enabled us to continue our activities in fifteen provinces.

Our results

What did we achieve in Indonesia?

Realisation: €931,260
Number of employees: 50



13,135

new leprosy cases were found, diagnosed, and treated in our programme areas



20,563

direct contacts of new leprosy patients received a single dose of rifampicin to reduce the risk of developing leprosy by 50-60%



2,203

health workers, community volunteers, accredited social health activists (ASHAs), and government health staff were trained on leprosy



294

people received vocational training to learn a trade



41

lives were improved with reconstructive surgery



604

children of leprosy-affected persons received financial support for their education



99

people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



19,850

community members were informed and educated on general disabilities to raise awareness



5

Disabled People's Organisations received assistance to promote participation of people with leprosy-related disabilities



18

people received a microcredit to help them become self-employed



116

persons with disabilities were helped to stand up for their rights

Story from the field

Motivated to fight leprosy



Mohammed's family was afraid of his leprosy. He was hidden indoors and could not go outside. Now he goes around the villages to tell people that leprosy is curable and that patients should not be locked away.

"When the first signs of leprosy emerged, I thought I was superman. My one arm had become numb. I could hold a match to it and not feel it burn. When my neighbours said it was leprosy, our world collapsed. My parents thought my illness was a punishment from God. I was no longer allowed to go outside the house. They hid me indoors and gave me a separate room. I always sat on the same chair, ate from the same plate with the same cutlery, and used my own towel. Not only my parents; the rest of my family too feared my leprosy."

Stigma worse than the disease itself

"These were the darkest days of my life. Even today, the memories can bring me to tears. After a year, by coincidence, my parents found out that one of our neighbours had had leprosy too, but was now cured. Only then did they take me to a clinic. Three years later, I too had been cured. But the consequences of the disease haunt me to this very day, 28 years later. My siblings are still ashamed of me. The stigma leprosy patients carry is probably more persistent than the disease itself. That is why I am so motivated to fight leprosy."

Taking action together

"I am the chairman of Permata Cabay Lamongan, a group of former leprosy patients. Together we fight the disease on East Java. The situation has improved a lot already. People affected by leprosy used to be completely cut off from their environment. Nevertheless, our work remains important. Every year, another 4,000 new cases are added. We go around the villages to tell people that the disease can be cured and that patients should not be locked away."

It is very important to involve the religious leaders in our work, especially the Muslim leaders. They can play an important role in pushing back the stigma. Just like the patients' families. Medication may stop the disease, but full recovery is only possible with family support."

Priority programme

Stop transmission of leprosy

Results in 2018

Besides implementing the Post-Exposure Prophylaxis (PEP) project and starting to adapt the SkinApp, we continued supporting the Leprosy Friendly Villages. We also provided supervision and technical guidance to province/district leprosy teams in ten well-defined fields such as early detection, diagnosis and treatment, handling complications and referrals, and coaching, and organised advocacy meetings. Our activities were carried out in 35 districts across 13 provinces. A start was made with the development of the PEPcom project in Indramayu district, West Java.

Lessons learned in 2018

The technical guidance provided to provinces and districts was assessed with the help of a newly developed tool, which enabled us to monitor progress. 2018 was also the first year that district meetings urged health centres to take ownership of and responsibility for the leprosy programme. The initiative reaped positive results but requires follow-up by District Leprosy Supervisors and Health Centre Leprosy Workers.

Plans for 2019

NLR will continue to improve the capacity of provincial and district leprosy supervisors and encourage innovative approaches to stop leprosy transmission. We will help the government scale up innovative approaches that prove to be cost-effective.



Highlighted project

Stop transmission of leprosy

Results in 2018

- In Indonesia, the “Stop the transmission of leprosy!” project experienced strong momentum in the last quarter of 2018: the mapping and perception study training workshops were completed. Subsequent fieldwork was performed swiftly and by the end of the year, nearly all data was collected for the study’s two components.
- Progress in mustering governmental and stakeholder support for the programme took place on two fronts in 2018. Firstly, the National Technical Working Group, led by the Ministry of Health with the involvement of other key stakeholders, met in September. Secondly, the Ministry of Health acknowledged the programme as a research intervention and all partners agreed that the National Institute of Health Research and Development should review the protocol and be actively involved.

Lessons learned in 2018

- Governmental oversight over the “Stop the transmission of leprosy!” project is tighter in Indonesia than it is in other countries. The Indonesian government maintains a close watch over the kinds of interventions that take place, the level of foreign involvement, and the permissions granted to publish data collected in the country. The government’s approach requires patience and carefulness in all communication, particularly when public officials are involved.

Plans for 2019

- Early 2019 we will organise workshops on mapping analysis and community education/behavioural change materials and methods. Context-specific mapping methodologies and materials will inform the full intervention.
- Extensive training of research assistants and field staff will take place before the first doses of PEP++ are administered at the end of the first semester or the beginning of the second semester.



Highlighted project

LPEP

Results in 2018

Since the project's launch in 2015, two different approaches have been implemented. The first approach administered single-dose rifampicin to the total population of a remote and isolated island in Southeast Maluku with a high incidence of leprosy. The second method reached a higher number of contacts (circa 40) per patient than average (circa 20) in a highly endemic district in East Java province. Both finalised data collection in 2018.

Lessons learned in 2018

Both approaches proved feasible and led to a reduction of new cases. These promising results motivate us to continue LPEP's activities in the coming years, working towards zero leprosy in the targeted areas.

Plans for 2019

The project's results and lessons learned will be shared with a wide audience of stakeholders in 2019. Based on its experiences with LPEP, NLR Indonesia plans to scale up the approach to other endemic areas. A gradual approach providing technical guidance through training, monitoring, and supervision will guarantee implementation quality.



Priority programme

Combined approaches to prevention and management of disability

In 2018, no combined approaches activities were carried out. In 2019, we will pilot courses for provincial and district supervisors and health centre staff, establish four combined self-care groups for leprosy and lymphatic filariasis, develop guidelines, and support the referral of cases requiring hospital care.



Priority programme

Disability-inclusive development

Results in 2018

Our Inclusion and Disability Programme enables fourteen organisations to lobby the government on disability-inclusive development strategies. Reliable data on persons with disabilities and persons affected by leprosy are now available at village and district levels and can be used by local governments and other stakeholders to make disability-inclusive plans. Governmental and other stakeholders are engaged and stepped up their commitment to disability-inclusive development.

Lessons learned in 2018

Although partner organisations own educational materials to raise awareness locally, these were never assessed on their effectiveness in reaching different audiences. As such, Behavioural Change Communication training courses and assessments given by NLR are required in 2019.

Plans for 2019

We will continue to strengthen our organisation and collaborate with partner organisations. A new decree (No. 16/2018) concerning the use of municipal budgets in 2019 clearly prioritises inclusive development. NLR will seize this opportunity to develop disability-friendly villages in collaboration with other stakeholders, championing the Community-Based Rehabilitation approach.



Highlighted project

Recovery assistance for people affected by leprosy in Palu and Donggala

On 28 September 2018, an earthquake with a magnitude 7.4 struck Central Sulawesi. The earthquake triggered a tsunami reaching heights of 4 to 7 meters and hitting Palu, Donggala, and Sigi.

Results in 2018

- In response to the disaster, NLR, in collaboration with GLRA, German Leprosy and TB Relief Association, ensured that the lives of people affected by leprosy and their families went back to normal, and patients got back on treatment.
- NLR also devised a needs assessment. To take away barriers, a team consisting of people affected by leprosy was trained to conduct the assessment.

Lessons learned in 2018

- We involved people affected by leprosy in the training and need assessment so they might gain the trust of the persons affected that will be interviewed. Seeing their contributions has been phenomenal.

Plans for 2019

- The assessment will be carried out in early January 2019. After this, plans for recovery assistance will be made, mostly covering protective footwear and self-help groups.



Priority programme

Reduction of stigma and discrimination

Results in 2018

To reduce stigma among government officials and people relating to those affected by leprosy, public awareness campaigns were rolled out in 2018. In Cirebon district, we offered and scaled up peer group counselling, which significantly reduced self-stigmatisation. By the end of the project, a book was published that encourages the health department to replicate peer counselling activities. In Sukoharjo and Blora District of Central Java, a task force was set up consisting of key stakeholders in the field of disability as well as government officials that share concerns about disability, leprosy, HIV/AIDS, TB, and other diseases that can cause stigma.

Lessons learned in 2018

In 2018, NLR Indonesia did not develop a specific strategy to reduce stigma and discrimination. Later on, however, in November 2018, there was a meeting at cross-country NLR level. Prior to this, NLR Indonesia staff discussed how to move forward in this priority programme and laid the foundations for the priority programme 2019 plan.

Plans for 2019

In 2019, internal capacity building, public awareness, and the development of peer counselling, or training of trainers for counselling, are listed to be implemented.





Story from the field

"I am entitled to education and work as much as everyone else"



Uswatun was diagnosed with leprosy only in eighth grade of junior high school. The most terrible time of her life began. Because the disease affected her looks, classmates and friends started avoiding her. Uswatun became depressed. Then a peer counsellor came by and Uswatun found new direction in life. She received financial support for higher education and became the school's champion. Now she feels it is her turn to help people affected by leprosy.

"At some point, I felt an unusual sensation in my skin, especially under my left eye. I started worrying and asked my mother to take me for medical examination. Since my mother's food stall is near a public health centre, that is where we went.

At the health centre, I underwent rigorous examination. After they checked every spot on my skin, a health worker informed me that I had leprosy and had to take medication for twelve

months. I could only be silent. I thought: 'leprosy must be a severe disease if I will be taking medication for an entire year.' I knew next to nothing about leprosy."



Dark era

“The medication caused my body to change. My skin started to become insensitive, bruised, and because my right foot grew bigger, I became physically weak to the point that I could not walk anymore. It was then that I started to experience stigma. Not only at school or in my community – but also internally. I started to stigmatise myself.

Weak and unable to walk, I stayed home from school for three weeks. When my father, who is a rickshaw driver, drove me to school in his rickshaw, I cried. I was sad, I felt so constrained. This worsened when my friends started avoiding me because they thought I was ugly. There was even a teacher who treated me badly for my condition.

From that point on I became depressed. My eagerness to study vanished, I was pessimistic, and almost stopped attending school. I felt insecure, lacked confidence, and felt embarrassed about meeting people. My grades dropped and I had no friends left. Because I heard people say I was ugly, I did not dare leave the house anymore. Even when visitors came over, I hid in my room. The situation left my parents terribly sad.”

Life’s direction

“In the midst of my darkest hour, I got in touch with a peer counsellor. She gave me hope and helped me find new direction in life. She took me to Cirebon to meet others affected by leprosy. No longer I felt lonely – I was so grateful. The sessions gave me new confidence and taught me that we – people affected by leprosy – are entitled to education and work as much as everyone else. Thanks to counselling, I found new hope and confidence, and started to believe again that I can succeed.

Once I graduated from junior high school, I felt confused. What should I do with my life? My family is poor, and my parents cannot afford paying for higher education. Then, NLR offered to support my high school education. It was a true blessing and I used the opportunity to the best of my abilities. I was very eager to study, work hard, and succeed.”

School champion

“My high school experience stood in stark contrast to that at junior high school. From 10th to 12th grade I was the school’s champion, I had good friends, and my teachers were very supportive. But then I graduated, and confusion kicked in again. I examined my options. Should I look for a job? Continue my studies? Get married? I applied for work but failed. I also applied for school, but that failed too. And then my prayers were answered. I received a scholarship! It enabled me to continue my studies at the Islamic State Institute of Syakh Nurjati Cirebon. I enjoy every day and my average grade is now 3.5 out of 4.”

Peers helping peers

“In March 2018, I was fortunate to join the Communication Forum of people with special needs in Cirebon. At the forum, I meet many inspiring people with whom I share and learn. I also participated in the counselling programme in Karangsembung Subdistrict. Here, a refresher course at Mimi Institute taught me counselling skills. It is now my turn to help people affected by leprosy – just like I was helped. I want to encourage them, and help them find direction in life.”



Nepal

NLR Nepal implemented Post-Exposure Prophylaxis (PEP) interventions and Inclusive Development interventions in close collaboration with authorities in province 1 (Eastern Province) and province 7 (Far Western Province), and in Parsa Districts (Province 2).

Our results

What did we achieve in Nepal?

Realisation: €292,033
Number of employees: 18



852

new leprosy cases were found, diagnosed, and treated in our programme areas



14,407

direct contacts of new leprosy patients were given a single dose of rifampicin to reduce the risk of developing leprosy by 50-60%



1,154

health workers, community volunteers, and government health staff were trained on leprosy



260

people received vocational training to learn a trade



46

lives were improved with reconstructive surgery



887

people were informed and educated on leprosy to raise awareness



899

people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



265

community members were informed and educated on general disabilities to raise awareness



10

Disabled People's Organisations received assistance to promote participation of people with leprosy-related disabilities



260

people received a microcredit to help them become self-employed



276

persons with disabilities were helped to stand up for their rights



110

people were provided with leadership training to guide and support others and groups

Priority programme

Stop transmission of leprosy

Results in 2018

Between 2015 and 2018, NLR Nepal implemented the Leprosy Post-Exposure Prophylaxis (LPEP) pilot in three Nepalese districts. Together with the government of Nepal, we implemented a Post-Exposure Prophylaxis (PEP) project in six more districts. The positive experiences and lessons learned inspired the national programme to scale up to other endemic areas in Nepal.

Lessons learned in 2018

- Integrating LPEP activities into the routine leprosy control programme is feasible.
- Piloting the LPEP approach proved successful in cooperation with the government and other NGOs.
- The government has been involved from the start, which shows their commitment and contributes to the future nationwide implementation of the programme.
- The government included the PEP approach in its National Strategy.

Plans for 2019

- In collaboration with the government, NLR Nepal will roll out the PEP project in twelve more districts.
- In collaboration with other NGOs, NLR Nepal will train and consult government health staff on a further expansion of PEP to other provinces.



Highlighted project

LPEP

Results in 2018

NLR Nepal started the LPEP project in 2015, with final data collection reaching completion in 2018. In total, more than 50,000 contacts of leprosy patients – of which 7,100 in 2018 – received single-dose rifampicin to reduce their chances of developing leprosy. During the project, 274 persons were diagnosed with leprosy, of which 37 in 2018. Training health staff was an important feature of the project. Training of more than 4,000 health workers reinforces health systems.

Lessons learned in 2018

To study the acceptability of LPEP activities, screening of contacts, and distribution of single-dose rifampicin, a sub-study was performed. While the study showed that activities were positively accepted among main stakeholders, some patients were reluctant to disclose their identity to neighbours. The study mainly underscored the feasibility of integration of LPEP activities with the routine leprosy control programme.

Plans for 2019

The results of the LPEP project and lessons learned will be disseminated among our major stakeholders in Nepal. In the project areas, single-dose rifampicin administration will continue as part of routine leprosy control.



Story from the field

"My family and I are closely monitored"



After a months-long search, Rameswor was told that he was affected by leprosy. He was terrified. Would his family await the same fate? Fortunately, Rameswor did not have to be in uncertainty for long.

"My wife and I live in the same house with our three children, two children-in-law, and six grandchildren. A doctor came by to examine us all. This gave me some peace."

One step ahead

"However, when the doctor told me that my son had leprosy too, at first I was shocked. But soon I felt relieved that it had been discovered in time. The rest of my family received preventive treatment. It greatly reduces the risk that they too become infected. I pray for them every day."

Getting better

"I used to grow rice and corn on the plot adjacent to our house, but it became increasingly challenging for me to do my work. I lost the strength in my hands and feet, and my body is covered in sores.

The doctor made it very clear that if I want to get better, I should be careful to take my medication. He also showed me how to best care for my ulcers and protect them. He keeps a close eye on my family and me."

Priority programme

Disability-inclusive development

Results in 2018

- By starting the Disability-inclusive development project in ten municipalities, NLR Nepal reaches approximately 32,000 people. The programme includes seven components: disability prevention, disability management, disability-inclusive development, PEP, leprosy control, water sanitation and hygiene, and organisational reinforcement.
- During the programme's first year, NLR Nepal built a good rapport with the municipalities. Municipalities already took ownership of the programme, incorporated the Disability-inclusive development programme in their periodic planning, allocated resources, and recruited additional staff for implementation. Some municipalities plan to declare themselves leprosy-free by 2020.
- NLR Nepal works with ten Disabled Person's Organisation. Nineteen leprosy-affected persons participate in the executive bodies of these Disabled People's Organisations.

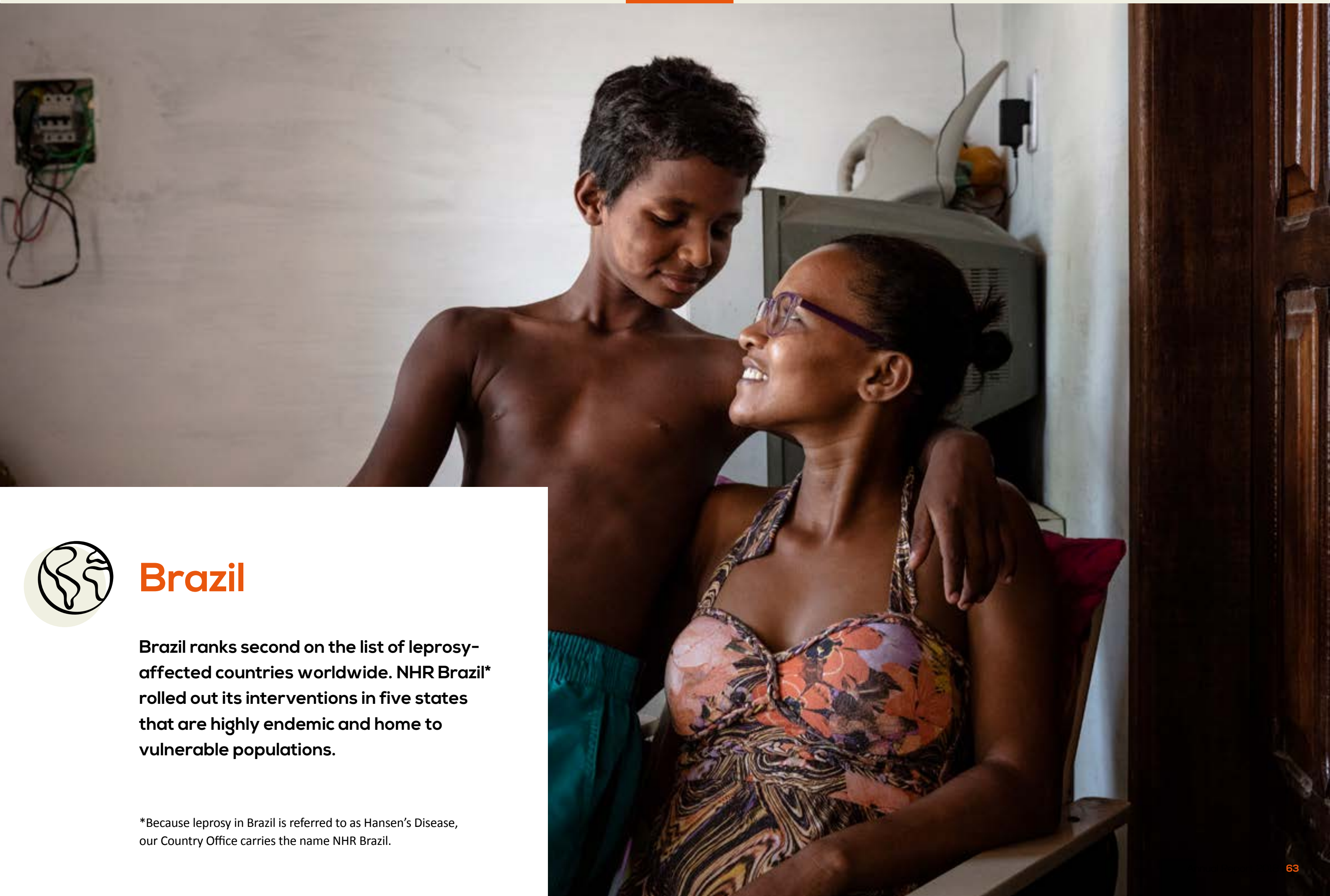
Lessons learned in 2018

- Communication with municipalities and requests for in-kind and financial contributions facilitated municipality ownership of the programme. Even before the project had officially started, municipalities contributed more than expected.
- NLR offered to coordinate a government population census on the municipal level. Doing so gave us the opportunity to include additional questions on disabilities and leprosy, strengthening our needs assessment and programme baseline.

Plans for 2019

- In 2019, we will continue to work in the ten municipalities where we started the programme as well as expand to another eight municipalities.





Brazil

Brazil ranks second on the list of leprosy-affected countries worldwide. NHR Brazil* rolled out its interventions in five states that are highly endemic and home to vulnerable populations.

*Because leprosy in Brazil is referred to as Hansen's Disease, our Country Office carries the name NHR Brazil.

Our results

What did we achieve in Brazil?

Realisation: €265,345
Number of employees: 7



1,679

new leprosy cases were found, diagnosed, and treated in our programme areas



24

existing self-care groups (formed before 2018)



1,156

health workers, community volunteers, and government health staff were trained on leprosy



41

people received vocational training to learn a trade



273

lives were improved with reconstructive surgery



397

persons disabled by leprosy and other diseases were trained in self-care to help prevent (the worsening of) disabilities



5,645

people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



6,694

community members were informed and educated on general disabilities to raise awareness



19

people were provided with leadership training to guide and support others and groups



260

people received a microcredit to help them become self-employed



67

persons with disabilities were helped to stand up for their rights



16,901

people were informed and educated on leprosy to raise awareness



Story from the field

“The self-care group boosts our self-esteem”



Maurineia suffered severely from leprosy. She finds support, however, at the self-care group in her neighbourhood where she has been a member for four years. Her cheerful character and leadership qualities even led her to become a coordinator. Attending the group boosts her self-esteem.

“It happened when I was nineteen. I barely finished high school and wanted to become a teacher or social worker. Because I suffered knee pain, I went to see a doctor. He thought I had rheumatism and prescribed medicines. Although I took my medicines, my health did not improve.

When patches started to develop on my skin as well, I returned to the health centre and was diagnosed with leprosy. Because the diagnosis came so late, both my hands and my feet became deformed. I had to give up my plans for the future, my dreams are gone.”

Overcoming stigma

“The self-care group I attend is an important source of support for me. We are thirty in total, and I have been a member and coordinator for four years now. At the group, we can discuss the problems we encounter because of our illness. It is a tight-knit community that strengthens our sense of self-esteem – we have really become friends.

Leprosy continues to be associated with stigma. It is like in the days of Jesus Christ, when we were called lepers and people did not want to come close out of fear of infection. My daughter Vitória often joins me to the self-care group. It is important to me that she learns to relate to people affected by leprosy, free from prejudice.”

Priority programme

Stop transmission of leprosy

Results in 2018

- We launched the “Stop the transmission of leprosy!” project in two municipalities.
- A study indicated that men over 60 are at risk in particular: their cases are detected too late or not at all. To improve their access to services, NHR Brazil raised awareness through media campaigns as well as trained 332 health professionals across two municipalities. Our activities drove up the detection of cases among this group and the detection of cases in general. The involvement of municipal authorities and health officials created a general sense of awareness about the need to fight leprosy.

Lessons learned in 2018

- NHR Brazil learned that diagnosis and timely treatment of leprosy is hampered by operational challenges at health services.

Plans for 2019

- The results of and learnings from our work targeting men over 60 will be discussed in early 2019 at a workshop with dermatologists, representatives of municipalities, and the Ministry of Health. The strategies produced during this workshop will be implemented by the health sector.
- We will pilot the use of the SkinApp at leprosy control programmes.



Highlighted project

Stop the transmission of leprosy!

Results in 2018

- In the Brazilian arm of the study, three different protocols – the perception study, the screening test pilot, and the mapping study – were approved during the last quarter of 2018.
- Laboratory testing of the Multiplex Lateral (ML) Flow rapid test using serum samples was evaluated and compared with antibody concentrations against Enzyme-Linked Immunosorbent Assay (ELISA) tests.
- The Brazilian team pressed for approval of the Opioid Risk Tool (ORT) screening test to be used for similar testing and field research purposes. Approval enabled the team to make all necessary preparations for the serological screening test pilot in early 2019. Results will allow the Scientific Steering Committee to determine which test to use, if any, in the full programme.

Lessons learned in 2018

- 2018 saw a full turnover in all key positions of the team coordinating “Stop the transmission of leprosy!” – Principal Investigator, Project Coordinator, and NLR Country Director – leading to a new beginning for the programme. As much as it is essential to possess the necessary skills and competencies, 2018 also underpinned the importance of team relations and interaction.
- Brazil lags a little bit behind the other countries. Therefore,

it took the key decision to split the overall study protocol into smaller protocols for separate ethical approval. Doing so allowed the team to achieve good progress in several of the study’s domains while awaiting full programme submission and approval.

Plans for 2019

- The team will continue to make progress in the smaller studies that have already been approved, starting with the screening test pilot. In one municipality, data collection for the perception study is nearly finalised. Case mapping will also be completed shortly, as the health information system in place facilitates the collection of GPS data of new leprosy cases.
- Final protocol submission and overall ethical clearance for the clinical trial is forecasted for the second quarter of 2019.



Priority programme

Combined approaches to prevention and management of disability

At this point, NHR Brazil runs 21 self-care groups across two states.

Results in 2018

- The use of a toolkit was piloted to measure the social and psychological aspects and burden of morbidity among self-care group members. NHR Brazil trained eight self-care group coordinators. To replicate the toolkit's use, the coordinators will serve as trainers of trainers.
- In Rondônia State, the programme addressed aspects of income generation. Group members participated in workshops and 52% (27 people) successfully started a small business to generate their own income. In Pernambuco State we collaborated with MORHAN, a social movement of persons affected by leprosy, and put more emphasis on empowerment of self-care groups.
- NHR Brazil trained the first group on leadership, where a number of group coordinators were included.

Lessons learned in 2018

- Health workers are key to NHR Brazil's self-care groups. Their involvement in the groups, however, can create a dependency on the availability and support provided by specific health staff.

- Over the years, NHR Brazil worked with 59 groups across eight states. As the large majority of these groups continue to exist after our withdrawal, we conclude our approaches produce long-term impact.
- Some self-care groups develop into self-help groups. When they do, they add income generation activities and/or address concerns and needs of persons affected by leprosy that need to be taken up by duty bearers. At this point, no clear strategy exists to promote the possibility for a self-care group to transition into a self-help group.

Plans for 2019

- NHR Brazil will develop a strategy to improve support of self-care groups and their transition into self-help groups.
- NHR Brazil will create new and more inclusive self-care groups, also taking up persons affected by other diseases.
- We will continue training self-care group coordinators on the use of the toolkit, as well as help the first group of trained trainers to apply the toolkit more widely.
- We will develop a second leadership model for persons affected by leprosy and other neglected diseases, as well as for leaders of social movements.



Story from the field

"The hidden suffering affects me deeply"



Occupational therapist Fabiana specialised in leprosy. Thanks to her commitment, a service and a self-care group for people affected by leprosy opened at the hospital where she works. Fabiana is fully invested in her patients – she considers them family.

"With leprosy still being a massive taboo in Brazil, late diagnosis is one of the hardest-to-tackle problems. The people affected suffer the sad consequences. I frequently receive patients already having developed leprosy-related disabilities by the time they consult me. That includes children. A timely diagnosis, on the contrary, can prevent damage."

Better information and support

"It saddens me that prejudice prevails. Most people do not want to come near persons affected by leprosy or touch them. The best way to change this is to provide better information: about the disease itself, how to recognise it, and what to do about it.

Besides the physical burden, I also get to see the hidden, emotional suffering that most leprosy patients endure. It led me to set up a self-care group that today counts 40 members. Under supervision, they openly talk about their disease. But we do not only talk, we also make trips together. Those are a lot of fun."

Priority programme

Disability-inclusive development

Results in 2018

In Jaibaras, a start was made with a new disability-inclusive community. Supported by MORHAN, a local team of persons affected and persons with a disability worked with the community to collect baseline data. This alone triggered widespread awareness about leprosy and disability issues among the general population. The efforts made clear that stigma is an important issue to be addressed.

- On local radio shows and social media, as well as at educational sessions at health centres and schools, NHR Brazil raised awareness about inclusion, stigma, and the rights of persons affected by leprosy.
- Discussions were initiated with school and church authorities on how to best address the topic of inclusion.
- The local Health Council was reactivated by the local Disability-Inclusive Development (DID) team. The Council now meets on a regular basis, with the active participation of health workers, community leaders, persons affected by leprosy, and those with a disability. The issues pointed out by the collected baseline data serve as input for the meetings.
- The Jaibaras team also organised sessions to raise awareness in their community. Team members indicated that already their lives have dramatically improved. Their growing self-esteem and changed perception of other community members make a big difference in their day-to-day reality.

Lessons learned in 2018

- High levels of stigma touch persons affected by leprosy.
- The Jaibaras team successfully joined persons affected by leprosy and persons with disabilities – other places appeared resistant to integration. Documenting the process in Jaibaras will help make SCGs more successful and inclusive in other municipalities.

Plans for 2019

- We will produce educational materials on inclusive development and Information, Education, and Communication materials for awareness-raising and training in healthcare.
- By strengthening the Jaibaras team, they can carry out follow-up activities – specifically targeting managers, educational professionals, and health unit personnel – and actively participate in the health council.
- We will present preliminary results from our Jaibaras work at scientific and/or political events to promote greater sustainability and understanding of our efforts.
- NHR Brazil will develop a strategy to support the transition of self-care groups into self-help groups.



Priority programme

Reduction of stigma and discrimination

Results in 2018

- In one of the most endemic municipalities of Brazil – Floriano, Piauí state – previous research indicated high levels of stigma. NHR Brazil used a specific instrument (the EMIC scale) to measure stigma in the community and towards persons affected; health professionals and persons affected discussed stigma in focal groups. During a workshop, results from all activities were presented and discussed, and context-specific interventions were formulated. Municipal authorities, healthcare and educational professionals, and persons affected were actively involved during the entire process. Their support helped formulate an agenda of compromises that will see stigma reduction activities implemented in 2019. By working with both healthcare and educational departments, the municipal government included the activities in its planning process and enabled uptake of specific activities in its services.
- With support from the Ministry of Health, 25 people (health professionals, MORHAN representatives, teachers, and researchers) were trained on the use of stigma instruments. The course taught participants how to assess and discuss stigma in communities and at health services.

Lessons learned in 2018

- Our work on stigma clearly indicated that stigmatisation amplifies suffering, hinders early detection, and undermines treatment.
- Identifying and addressing stigma-related issues requires the active involvement of all municipal stakeholders.

Plans for 2019

- We will replicate our Floriano activities in other municipalities.
- We will develop a course on stigma using a problem-based learning methodology that builds on the scale of stigma.
- We will develop ways to effect stigma reduction in general and target health professionals through the internet.





Story from the field

"I draw on my own experiences"



Kássia Pollyane Gomes Medeiros helps people overcome their struggles caused by prejudice and stigma against persons affected by leprosy. She leads a self-care group in Recife and during meetings at a health unit, offers support to people with different stories and problems. "Often participants are not heard. They do not have others to talk to. Their families and friends reject them."

In 2018, Kássia's self-care group discussed the rights and duties of people affected by leprosy. Discussions emphasised the need to finish treatment and addressed discrimination at the workplace and in communities. During the year, NHR Brazil's support also enabled the group to instruct participants on self-care. Members received sunscreens, towels, buckets, and skin lotions. Finally, supplies were provided for "Mirror Day." This event encourages participants to look in the mirror and observe the functioning of their nerves and possible wounds.

pains in her left arm. At the time, she worked as a dental assistant at two public institutions.

Kássia did not experience stigma herself. During and after her treatment, however, she struggled with constant pains and neuritis in her left arm. She stayed away from work during the following three years and was relocated to administrative positions upon return. Because she cannot use her left arm like before, she overuses her right arm. "I felt the same pain the participants experience. This makes it easier for me to talk to them. When I tell my story, they feel more comfortable to share their thoughts."

Sharing thoughts and feelings

Along with a nursing student from the University of Pernambuco, Kássia takes care of the group and offers emotional support. A member of the social leprosy movement and affected by the disease herself, Kássia draws on her own experiences in the support she offers. Her diagnosis was confirmed one month after she felt the first

In 2014, Kássia joined the Social Movement for Reintegration of People Affected by Hansen's Disease, which partnered with NHR Brazil on a project in Pernambuco in 2018. "The partnership is extremely valuable. We do activities together, discuss the disease in communities, and support the affected."



Phasing out our work in Nigeria and the Mekong region

After seeing a structural decrease in income, in November 2016 we decided to phase out funding of two of our offices: NLR Nigeria and NLR Mekong. With both teams we agreed on a transition plan of two years. In 2018, we almost completed this process. Transition funding will come to an end in 2019.

In both countries, NLR's teams started procedures for registration as local NGOs in 2018 (Nigeria and Mekong). We are looking forward to continued collaboration inside NLR's Alliance, enabling them to tap into insights acquired and methods developed by NLR.



The transition phase

Nigeria

In 2018, we studied, evaluated, and documented two innovative approaches that we developed over the last years. Towards the end of the year, we shared our main recommendations at a national workshop with all relevant stakeholders, including representatives of the Ministry of Health and other leprosy organisations. The studies focused on:

- Involving traditional healers, community volunteers, and patent medicine vendors in recognition and referral practices in low endemic areas to increase case finding.
- A slimmer, smarter, and more cost-efficient approach to leprosy control by way of fewer health clinics providing multi-drug therapy and better-trained General Health Workers in the General Hospitals and a limited number of Primary Health Centres.

Realisation: **€155,446**
Number of employees: **14**

Both approaches were evaluated on programmatic and economic effectiveness. The evaluation's main conclusions were presented and discussed at the national workshop:

- Compared to routine practice, the approach is cost-effective and offers better value for money in leprosy control.
- Evidence suggests this is a low-cost leprosy case detection strategy assessed from both the providers' perspective as well as that of patients and their families.
- Involvement of leaders and volunteers was a massive contributor to the programme's success, reducing costs while helping identify suspects.

The workshop concluded the approach is highly beneficial and recommended it for adoption by policymakers.

NLR will continue organisational support for the local NGO, called Leprosy and TB Relief Nigeria, until mid-2019 (June 30, 2019).



The transition phase

The Mekong Region

NLR Mekong successfully sourced funding from Liliane Fonds for its inclusive education projects; from Peerke Donders Foundation for prosthesis care and continued school support to children originating from poor, leprosy-affected families; and from Sasakawa Memorial Health Foundation (SMHF) to continue its integrated rehabilitation projects in Kontum and Gialai. Alongside the Vietnam Association for Education for All, NLR Mekong implements the project “Improving Sexual Reproductive Health Rights for the Deaf” – an initiative funded by Aus4Skills.

NLR Mekong brought in an organisational consultant to plan and establish a local organisation in Vietnam. The new organisation, called Research Centre for Inclusion, was legally registered in November 2018. It operates as a Vietnamese non-governmental organisation under the umbrella of the Southeast Asian Research Association of Vietnam. The Research Centre for Inclusion gradually takes over NLR Mekong’s expertise, experience, and network in the Mekong region, starting its operations in January 2019.

Realisation: **€723,856** Number of employees: **5**



11,847

direct contacts of new leprosy patients were given a single dose of rifampicin to reduce the risk of developing leprosy by 50-60%



2

Disabled People’s Organisations received assistance to promote participation of people with leprosy-related disabilities



104

persons received financial support for their education



360

persons with disabilities were helped to stand up for their rights



1,574

people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses



4

people received vocational training to learn a trade



36

people were provided with leadership training to guide and support others and groups



Completed project in 2018

These Shoes are Made for Walking in Vietnam

Funded by the Dutch Postcode Lottery and executed in partnership with Fontys University for Applied Sciences and Liliane Fonds, NLR Mekong established an international training course for Orthopaedic Shoe Technology at the Vietnamese Training Centre for Orthopaedic Technologists (VIETCOT) in Hanoi, Vietnam. The project was completed in 2018.

Overall results of the project

- We developed and set up an international training course for Orthopaedic Shoe Technology in Hanoi.
- Thirty students from across Southeast Asia successfully completed the course. Another seven students will graduate in March 2019.
- Students set up eight workshops for orthopaedic shoe-making in their home countries.
- The training course, originally targeting Southeast Asian students, now also receives students from Africa.
- VIETCOT and Fontys University for Applied Sciences established a permanent partnership.

The project took longer than initially planned: five years instead of three. This was due to long delays in the delivery of machinery in a number of countries, especially in Myanmar and Vietnam.

Plans for the future

- Full ownership of the international training course in Hanoi, and thereby its future, now lies with VIETCOT.
- NLR and Liliane Fonds seek to launch an African edition of These Shoes are Made for Walking. The need for orthopaedic footwear, especially among children, is equally present in Africa. A first mission established contacts with VIETCOT's sister institutions. Sourcing funding will be the project's biggest challenge.





Fundraising & communi- cations

Fundraising

In 2018, NLR could once again rely on a supportive, committed, and generous group of donors to realise its mission. We raised funds from private donors as well as from institutional partners. Their gifts are much, much more than just a donation. At the heart of it, our fundraising builds bridges between our donors envisioning a world without leprosy and our beneficiaries: persons affected by leprosy.

Our donors and us, we share the same dream: together we work towards the day when leprosy no longer destroys lives. We are passionate about seeing that dream become a reality.

Private donors

Thanks to the financial contribution of our private donors, we can continue to carry out our programmes on a structural basis. Income from donations and gifts increased when compared to 2017 with 2% to €2.5 million. The number of donors actively supporting NLR decreased from 45,660 in 2017 to 44,862 in 2018 (a change of -1.7%). This is mostly due to retirement, old age, and decease.

To recruit new donors, we sent out two prospect mailings to recipients who never donated to NLR before. As a result, we welcomed 2,218 new donors. In 2018 we extended our donor care programme with a greater focus on stronger, long-term relationships. For mid-level donors we developed a dedicated programme, enabling them to support a project that trains volunteers in Mozambique.

Legacies

In 2018, we invested more effort in the promotion of legacy donations. Our research shows that Dutch people are willing to leave legacy donations to NLR, but do not always know how. Therefore, we informed the Dutch public and our donors in particular on this subject: why legacy gifts are so important to our work and how to leave a legacy gift to NLR.

In 2018, the total income raised from legacies was €4.1 million. We are deeply grateful that so many were willing to collaborate with us towards our goal – a leprosy-free world – even after they are no longer with us. In 2019, strengthening our legacy programme and continuing to inform the Dutch public about this way of contributing, will remain a key priority.

Why did people donate to NLR in 2018?

People support NLR for very special reasons. Below you find a few examples of donors and their considerations. It is thanks to their collective support that our shared dream – a world free of leprosy – is coming true.



“ I have worked with people with severe physical disabilities for sixteen years. It strikes me that people affected by leprosy can become disabled and socially excluded for life. ”

Alie Schutten



“ As a child I was touched by a story of a Belgian priest. He devoted his life to missionary work among leprosy patients on Molokai, a Hawaiian island. To this day, I deeply admire people who dedicate their life to helping those affected by leprosy. ”

Riet Blom



“ Leprosy is treatable. It is finite and not a bottomless pit. How beautiful would it be if leprosy were eradicated from this world? ”

Ellen Hoog-Antink

Friends of NLR

Organising their own fundraising activities, supporters nationwide have demonstrated their commitment to people affected by leprosy. We highly value our supporters and consider them true ambassadors of our cause. In 2018 their efforts resulted in substantial donations:

Collectors

In the weeks approaching World Leprosy Day 2018 (28 January), our national door-to-door collection was carried out by around 350 volunteers, raising a total of €15,000.

Leprosy shop in Deventer

Volunteers at the Leprosy shop in Deventer raised €20,000 with the sales of second-hand items. We spent the funds on our self-care groups in India.

Dutch Mayors' Soccer Team (NBE)

The NBE played against six different opponents: business clubs and companies related to Dutch Premier League Football Organisations. With their teamwork, the NBE raised €8.491 for the fight against leprosy.

Comenius College and Zuider Gymnasium high schools

High schools “Comenius College” in Capelle aan den IJssel and “Zuider Gymnasium” in Rotterdam organised various fundraisers for Vietnamese people affected by leprosy, amounting to a total of €37,000. In October, eight pupils travelled to Vietnam to volunteer at Quy Hoa leprosy village, a community that is home to around 500 people affected by leprosy. The pupils self-supported their trip.

Events

Donor event

In light of our mid-level donor programme, in November 2018 we organised an event for donors who gave towards a specific project in Mozambique. With seventy donors attending, the event provided a fruitful social setting to meet donors face-to-face and inform them about the project – which thanks its progress to their contributions.

We received very positive feedback from attendees, inspiring us to continue organising donor appreciation events in 2019 as a way of fostering personal relationships with our donors.



Institutional partners

In 2018, we welcomed new institutional partners and deepened existing partnerships. Our efforts resulted in income raised from partners such as EDCTP, COR-NTD, and Liliane Foundation. Fifteen proposals were accepted in 2018 against eleven in 2017.

In 2018, we sustained our networking efforts and continued investing in relationships with other NGOs and institutional partners. This resulted in collaborative proposals acquiring new donors.

Extracting lessons from our institutional fundraising efforts, in 2019 we will intensify donor compliance improvement activities and clarify roles and responsibilities in the development of proposals.

Contribution from the Dutch Postcode Lottery

Since 1996, we have been a beneficiary of the Dutch Postcode Lottery. We receive an unearmarked annual contribution of €1,350,000. Thanks to the participants of the Dutch Postcode Lottery and their generosity, we can help thousands of people affected by leprosy every year.

In addition to the annual contribution of the Dutch Postcode Lottery, in 2017 we received €9,375,000 from their “Dream Fund.” This donation goes towards our five-year “Stop the transmission of leprosy!” project.

The “Dream Fund” contributes to our dream preventing people to develop leprosy and stopping the transmission of the leprosy bacteria.



Communications

Sharing stories from the field with our donors is an important part of our work – it is they who make it possible. Through these stories, donors get a taste of the impact their giving has. They get to see that lives are truly changed. Communicating about our impact also helps us reach prospect donors.

Brand awareness

Because we need to stand out in the charity marketplace, brand awareness is crucial to NLR. More than ever before, we need to demonstrate the uniqueness, effectiveness, and relevance of our cause – we need to prove that our cause is worthy of support. In June 2018, an external consultant conducted a baseline study that lays the foundation for a new brand strategy. To evaluate the impact of our new approach, the study will be repeated in 2020.

	Baseline study 2018	Goal 2020
Brand awareness	44%	47%
Brand strength score	11th place on the ranking of International Aid NGO brands in the Netherlands	9th place on the ranking of International Aid NGO brands in the Netherlands

Inspiring & connecting with private donors

Newsletter – “De Klepper”

In our donor newsletter “De Klepper,” we share with our donors the impact of their support: personal stories of persons affected by leprosy, case studies, and programme highlights. In 2018, we published five editions of the newsletter.

"Mijn bijdrage is nu echt meer waard"

Als kind werd Riet Blom geraakt door een verhaal van een pater die leprapatiënten hielp. Doneren aan de Leprastichting was voor haar dan ook een logische keuze. Dat doet ze al jaren via een periodieke schenking. "Het heeft voor mij fiscale voordelen, en de Leprastichting is voor langere tijd verzekerd van mijn steun."

"Mijn ouders legden thuis de nadruk op missionarissen die hun gezondheid in de waagschaal stelden om anderen te helpen. Ik herinner mij een verhaal van een pater die naar een eiland ging waar leprapatiënten woonden. Hij leefde daar samen met hen en kreeg uiteindelijk zelf ook lepra. Als kind raakte het mij dat hij zijn leven volledig in dienst stelde van het helpen van leprapatiënten. Ik heb daar nog altijd diepe bewondering voor."

Langre termijn

"Al vanaf 1981 steun ik de Leprastichting. Sinds 2004 schenk ik periodiek. Vanwege de fiscale voordelen. Mijn bijdrage is nu echt meer waard. En ik vind het administratief wel zo gemakkelijk dat mijn notariale akte kan doorlopen tot ik er niet meer ben. Bovendien weet de Leprastichting nu op welk bedrag ze de komende jaren kan rekenen, waardoor zij beter lange-termijnprojecten kan aanpakken."

In alle afleveringen die lepra met zich mee brengt, vind ik het belangrijk om het positieve te blijven zien. Dat zijn we ook wel verplicht aan de mensen die in het verleden, en ook nu, risico's durfden te nemen om leprapatiënten te helpen."



De boeken van Anthony van Kampen maakten die indruk op Riet Blom. In Brazilië kwam Van Kampen in contact met een missionaris die hem meenam naar een leprakolonie.

"Met mijn winkel kan ik mijzelf en mijn dochter onderhouden"

Bilma kreeg lepra toen ze tien jaar was. Door het stigma dat in India op lepra rust, kwam ze nooit buitenshuis en ging dus niet naar school. Ondanks dat, wist ze te ontsnappen aan een leven waarin ze afhankelijk is van bedelen. Ze begon een winkel met een lening via één van onze zelfhulpgroepen. De winkel zorgt voor geld om eten, kleding én het schoolgeld voor haar dochter Laksmi te betalen.

"De zelfhulpgroep, waarvan ik lid én voorzitter ben, heeft een startbedrag gekregen van de Leprastichting. Dit geld kunnen wij investeren. Als groepjesden kunnen we geld lenen om een bedrijf te starten of voor medische hulp. Vervolgens betalen we het in termijnen terug."

Eigen geld verdienen

"In een notitieboek houden we precies bij hoeveel geld iedereen geleend heeft. En dat wordt netjes met rente terugbetaald. Er is een maximum van zes maanden om het geld terug te betalen.

Dankzij de zelfhulpgroep heb ik nu een winkel. Ik verkoop snoep, eieren, zeep en andere benodigdheden. De zelfhulpgroep geeft mij veel zelfvertrouwen. Ik verdien nu mijn eigen geld, waardoor mijn dochter naar school kan en een betere toekomst kan opbouwen. We maken weer deel uit van de samenleving."

Bekijk de video van Bilma op: www.leprastichting.nl



Voor trots laat Bilma haar winkel zien, die ze dankzij de zelfhulpgroep nu heeft.

De Leprastichting verzorgt u op gezamenlijke wijze de Algemene Verordening Persoonsgegevens (AVG) en haar afgeleide wetgeving. Als u voor meer informatie op leprastichting.nl wilt, kan de Leprastichting verzocht worden 3 keer per jaar per e-mail als de afgeleide wetgeving van toepassing is. Indien u niet langer deze e-mail wilt ontvangen, kan u contact met ons op via info@leprastichting.nl of 020-3900500.

Postbus: Postbus 10000, 1008 HA Amsterdam
Telnummers: 020 390 50 00 | E-mail: info@leprastichting.nl
Internet: www.leprastichting.nl
BANK: 20000 NL00 NG00 2000 2000

Partij: Uitsluitend van den Heuvel, Jan Joseph Dirk, Leprastichting
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De Leprastichting is één van de 112
 Nederlandse verenigingen die samen
 vormen de Nationale Postcode Loterij.

Online & social media

In 2018, NLR revamped the design and content of its websites www.leprastichting.nl (Dutch) and www.NLRinternational.org (international). The redesigned websites were launched in January 2019. During the strategy phase, we decided to discontinue our integrated online store. The new websites feature a captivating layout, are user-friendly on desktop, tablet, and smartphone, easy to navigate and read, and contain tale-telling photographic and video graphic imagery. Based on data analysis via analytic tools, we will continue to develop and optimise the websites in 2019.

In 2018 we also switched from driving quantity to driving quality traffic. In the past, our online store for crochet items attracted a disproportional share of our website’s traffic. With the link between our mission and our crochet activities being too slim, we decided to cut back on crochet-related content. Today, we seek timely interaction with relevant social media followers and website visitors that are interested in our mission. In the short term, our decision yielded a decline in traffic – visitors to our online store now move to alternative suppliers. However, we believe that attracting relevant followers will, in the long term, benefit our cause more. By publishing relevant content and storytelling we will build long term relationships with (potential) donors that are interested in and committed to our program work.



Handling of complaints

At NLR, we take complaints very seriously and do our utmost best to handle them in a satisfactory manner. Any complaints are recorded in our register, in accordance with the procedural requirements of ISO 9001:2015.

In 2018, we received ten complaints about our fundraising. Three donors filed a complaint regarding the use of the term “annual contribution” in our direct mailing of January, when they were already donating by direct debit; two complaints concerned the fact NLR has a bank account with Dutch bank ING; two complaints concerned the level of our director’s remuneration; one donor made a complaint for not receiving a thank-you letter after having donated to NLR; and one complaint concerned the incorrect mentioning of a donor’s bank account number in a gift request”. Lastly, one donor complained about our use of telemarketing as a tool to win donations as a reminder of a direct mailing campaign.

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.

Protection of personal data

NLR places a high value on data privacy. We process personal data of donors and stakeholders with extreme care. We comply with Dutch law and the European Union General Data Protection Regulation (GDPR), which came into force on 25 May 2018. The privacy statement on our websites explains how, and to which purposes, we process personal data. It also explains the privacy rights of our donors.

Media

Awareness-raising remains crucial to our work. We do this, among others, via the media.

On World Disability Day 2018 (3 December), Dutch newspaper Trouw published a thematic supplement devoted to the full participation in society of people with disabilities. In length, the publication covered our work on prevention and management of disabilities. The newspaper reported on the story of a Brazilian woman who suffers from a leprosy-related disability and became a powerful leader of one of our self-care groups. Trouw also published an extensive feature article on Southeast Asian graduates from our international training course for orthopaedic shoe technology, who set up workshops in their home countries.

Ambassadors

The importance of our ambassadors cannot be overstated. They have seen our work with their own eyes and convey the heart behind our cause to the Dutch public. By volunteering in campaigns and events, and by promoting NLR in their own network, ambassadors help raise awareness about leprosy.

Actor Huub Stapel

Dutch actor Huub Stapel has been an invaluable ambassador to NLR ever since he came on board in 2013. In 2018, Huub travelled to India to visit a leprosy colony in New Delhi. At the colony, he had deeply moving encounters with people affected by leprosy and their families. With his own eyes and ears, he saw and heard how leprosy marks their lives and how NLR makes a positive impact on those affected and their families. We captured these emotional moments and will use the visit's photo and video materials for impactful storytelling to raise awareness about leprosy, demonstrate the impact of our work, and for (online) fundraising.

“

I was very young when I heard about leprosy for the first time. I learned about the disease in the stories of Belgian priest Damien – I will never forget. The stories I heard then and the stories I hear today are a big driver to promote the life-changing work that NLR does. ”

Huub Stapel

Cartoonist Andrea Kruis

Andrea Kruis followed in the footsteps of her father and cartoonist Jan Kruis, who passed away on 19 January 2017. For more than fifteen years Mr Kruis was an invaluable ambassador to NLR. We will be forever grateful for the impact he made. Five months after his passing away, his daughter Andrea travelled to India to shoot Dutch TV show “Wie maakt het verschil?” Taking her pencil along, in 2018 Andrea turned her experiences into an animation about leprosy and the work of NLR, starring best friends “Fransje” and “Marie” from “Vijftien en een half,” the Dutch cartoon series drawn by Andrea herself.

“

My father described leprosy as an affront to human dignity. And I couldn't agree more. NLR helps people who help people affected by leprosy. Which is all that matters. With my own eyes I have seen NLR make a powerful difference to those affected by leprosy. They really put their heart and soul into everything they do to help the affected. ”

Andreas Kruis

Crochet guru DenDennis

In 2015, creator of Dutch cartoon series “Jan, Jans en de kinderen,” Jan Kruis, made his beloved comic family available as crochet patterns. Since 2015, every year crochet guru DenDennis designs a new crochet pattern inspired by the famous comic characters. The patterns are sold to raise funds for NLR. In 2018, DenDennis designed the fourth and last pattern – Jeroentje – as we decided to discontinue to the project due to a missing relationship between crochet and our mission.

“

It is a pleasant thought that I can use my passion for crochet to serve people affected by leprosy. The patterns I designed for NLR were made with love. ”

DenDennis





Our organisation

Our staff

A solid organisational structure creates opportunities to enhance efficiency and effectiveness. Solidity as opposed to rigidity. 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.

Staff composition

NLR's International Office is based in Amsterdam, the Netherlands. Here, our staff is comprised of 33 employees (26.3 FTE) working across four departments. In 2018, the management and execution of field activities were delegated to five professional Country Offices located in Mozambique, India, Indonesia, Nepal, and Brazil. Together, these Country Offices employ a total of 167 employees. Two Country Offices, in Nigeria and the Mekong Region, with a total of 19 employees, are transitioning into independent NGOs. Phasing out of NLR funding neared completion by the end of 2018.

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 the staff at the International Office.

In 2018, a new Employee Representative Body was formed and took on its advisory role in November 2018. In 2019, NLR's Terms of Employment will be benchmarked and revised and will be subject to advice and consent of the Employee Representative Body.

Organisational development

In order to make our operations more sustainable in local contexts, we designed the NLR2020 project: we transform our local offices into locally registered and governed organisations that collaborate as part of an NLR Alliance.

In June 2018, two external auditors performed a mid-term review of the project. The auditors concluded that the project is well underway and that capacities to manage programmes and raise funds have increased across the organisation as a result of NLR2020. They also concluded that continued capacity strengthening is needed.

Moreover, the auditors recommended we speed up the process of forming the NLR Alliance. We adopted the recommendation and our work during the second half of 2018 led to the start of the NLR Alliance in early 2019. At the end of 2018, three local organisations were established in Nepal, Indonesia, and India. The Alliance enables its members to collaborate towards our common goal, together learning from best practices, lobbying at the international level, and raising funds.

Brazil

With the start of PEP++ interventions, NHR Brazil took on additional staff in 2018. In 2019, NHR Brazil will prioritise further strengthening of its team, to be prepared for the transition into a local NGO.

Indonesia

All throughout 2018, in Indonesia we enhanced our internal operational and financial management procedures; capitalised on monitoring and learning tools; and strengthened the links between our leprosy control and disability inclusion activities. We made preparations to set up the local NLR Indonesia foundation, which is to be registered in January 2019.

India

As a local NGO, the NLR India Foundation (kap) was registered in 1999. With NLR2020 underway, NLR will make this NGO more independent. Statutes have been amended and new, independent board members have been added in 2018. This process will be stepped up in 2019.

Mozambique

NLR Mozambique set up a small team in Nampula, relocated existing staff, and hired additional staff to improve the quality of our interventions and to be closer to the affected population. In 2019, we will continue investing in the development of our NLR staff to sustain the delivery of quality support and prepare for the transition into a local NGO.

Nepal

In 2018, a new director was appointed at NLR Nepal. To expand our programme monitoring and evaluation as well as our fundraising activities, the country team was extended by two FTE. Our centralised financial department has been strengthened through training and coaching activities performed by professional consultants. A Nepalese NGO (NLR Nepal) is to be registered in 2019 and will take over responsibilities from the current Country Office in the near future.

Integrity management

In 2018, NLR intensified and improved its internal mechanisms and awareness on issues and complaints related to integrity. During a Round Table session in spring, codes and regulations were updated and discussed with all managers. Discussion with staff across all our offices followed suit. Upon finishing the information and awareness discussions, in 2018 NLR's new code of conduct was signed by all staff.

Starting from 2018, every year our staff will refresh its awareness of our Code of Conduct and related regulations. This will be done by discussing workplace cases and examples and relating them to the Code of Conduct. Integrity risks and necessary controls have been included in the annual risk analysis, which is part of our annual planning and reporting cycles. Our integrity policies and practices are coordinated by NLR's HR officer, while senior management remains responsible.

The following integrity policies and protocols are in place. Together, they form the organisation's integrity framework:

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

With an effective integrity system in place, integrity issues will be reported and handled appropriately. In 2018, three issues were reported from Country Offices.

At one of our Country Offices, a conflict between two staff members neared escalation, with one party blaming management for not preventing and resolving. Our new Country Director managed to bring parties together and settled the dispute in a satisfactory manner for both.

There was a suspicion of theft of an item belonging to one of our staff members. The case was discussed in the team, and staff members who could have been involved were warned and monitored.

A dismissed staff member of one of our Country Offices complained about management style and unmotivated dismissal. The complaint was still under investigation by the end of 2018 and will be concluded in early 2019.

Governance and supervision

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, 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. In 2018, the Supervisory Board consisted of the following members:

A. van Ojik – Chairman

First term, until 1 January 2020

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

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.

R.L.J. Greveling – Chair Financial Audit Committee

Second term, until 31 December 2021

- Director of Finance, Stichting Koninklijke Visio (until 1 September 2018).
- Partner KPMG Accountants N.V. (since 1 September 2018).

Mrs E.J.C. Bongers

First term, until 19 May 2021

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

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

First term, until 1 April 2019

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

M.R.A. van Cleeff

First term, until 1 June 2019

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



Executive Board

J. van Berkel – CEO

- President of ILEP, International Federation of Anti-Leprosy Associations.
- Chair Board of Directors Goede Doelen Nederland (Dutch branch organisation for charities).
- Board member SBF, Samenwerkende Branche Organisaties Filantropie (Collaboration Dutch Philanthropic branch organisations).
- Director/Chair Executive Group LRI, Leprosy Research Initiative.
- Member Board of Directors Support Fund Dutch Händel Society.

The Dutch Act on Management and Supervision (Wet Bestuur en Toezicht) requires gender diversity in the appointment of Supervisory Board members. At least 30% of seats must be occupied by women and at least 30% by men. Our Supervisory Board meets these criteria with a current ratio of two female members to four male members.

Proceedings of the Supervisory Board in 2018

Upon their annual visit of the International Office and meetings with NLR's staff in September 2018, 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 its impact, Members of the Supervisory Board are expected to visit an NLR field programme at least once during their term. In 2018, two members visited the NLR Country Office in Indonesia and met with staff, persons affected, and important stakeholders. During the visit, a new Memorandum of Understanding – arranging the collaboration between NLR and Indonesia's Health Ministry – was signed.

Moreover, the Supervisory Board evaluates its own functioning on an annual basis. In its 2018 evaluation, the Supervisory Board concluded it had sufficient access to information needed to supervise the Managing Director. The Board also determined the agenda for its 2019 meetings. During the years ahead, the Supervisory Board will put a stronger emphasis on supervising the impact of NLR's programmes.

In 2018, the Supervisory Board met five times:

- 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 at every quarterly meeting.
- In May, the Board approved the 2017 Annual Reports of NLR and the Leprosy Research Initiative (LRI).
- At its December meeting, the Board approved the 2019 Annual Plans and Budgets of NLR and the LRI.
- In addition to its quarterly meetings, in September the Board discussed the mid-term review of the NLR 2020 project. It approved the continuation of the project and the formation of the NLR Alliance

The Supervisory Board also 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 Regulation for the Remuneration of Directors of Charities (Dutch: Regeling Beloning Directeuren van Goede Doelen) which is part of the Qualification System Charities (in Dutch: Erkenningssysteem Goede Doelen). Compared to positions of similar complexity and responsibility, the Supervisory Board considers the Managing Director's current remuneration fair and reasonable.

In its consideration, the Supervisory Board regards the position of NLR's Managing Director as more than a fulltime job. It is a role with great responsibilities that demands high-profile professional performance. The Managing Director is in charge of an international organisation that raises over €10,000,000 per year, employs 32 employees in Amsterdam and 186 in the Country Offices, receives the support of approximately 44,862 donors, and leans on 350 volunteers. An organisation also, that 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. The most recent update took place in 2017. The Board concluded that the remuneration policy was performed in accordance with the regulations. The 2018 annual salary of the CEO Mr Jan van Berkel was €117,181 (1 FTE/12 months). Van Berkel donated his remuneration of €5,000 as chair of Goede Doelen Nederland to NLR. For further details, see page 22 of the Annual Accounts of NLR.



Learning organisation

Risk analysis & control

From the annual risk analysis that all Country Offices and departments perform, shortage of revenues continues to be considered the largest threat to the continuity of NLR's operations. Training in Institutional Fundraising aims to help Country Offices tap into a more diverse range of income sources. Also, the work of the Dutch Fundraising Department stabilises and where possible increases income from private donors and legacies.

Staff security is the second-largest threat. In several countries where NLR has operations, there is a high incidence rate of traffic accidents. Strict security procedures for staff travels are continuously updated and revised.

In March 2018, the Supervisory Board approved an updated 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 2018.

In 2018, special attention was paid to inappropriate behaviour. In this light, our Code of Conduct was signed by all staff. Also, an Anti-Fraud & Anti-Corruption Policy, as well as a Complaint and Whistle-Blower Policy, are in place. The Dutch NLR policy on inappropriate behaviour was translated into English to help Country Offices make their own versions: much of the content is context- and culture-specific. Discussions were held during our Round Table meetings. All NLR departments and Country Offices organised sessions on safeguarding measures and appropriate behaviour; at the International Office an instructive meeting was held with the International Office's Confidential Advisor.

Another risk relates to new laws and regulations. Specifically, the European Union General Data Protection Regulation (GDPR) required our attention in 2018.

The EU General Data Protections Regulation

In May 2018, the European Union General Data Protection Regulation (GDPR) came into effect. Therefore, a privacy policy was developed, privacy statements were updated, a data register was created, data processing agreements were made and signed, and data security procedures were improved. We implemented a procedure to report and assess data incidents. We also developed procedures enabling our donors and other stake-holders to exercise their right to access, rectify, and erase personal data. Finally, we organised staff awareness sessions.

ISO certification

In November 2017, NLR was awarded the ISO 9001:2015 and the sector-specific ISO 9001:2015 Partos certifications. Certifications remain valid for three years. In 2018, the first intermediate audit was executed by an external quality auditor. No considerable shortcomings were identified. The second intermediate audit will be performed in 2019. The certification will be renewed in 2020.

Corporate social responsibility

NLR operates on a carbon-neutral basis. In 2018, our CO2 emissions from air travel and printing were compensated by contributions to sustainable energy projects. In accordance with the guideline "Financial Management of Fundraising Institutions," which was issued by Goede Doelen Nederland (Dutch branch organisation for charities), our starting point in the management of our reserve funds is the preservation of our capital. We invest our reserve funds exclusively in investment products offered by governments and companies that respect human rights, reject child labour, and manage their operations sustainably.



Partners & collaborations

Not any organisation can fight leprosy on its own. If we are to make progress at all, we need the help and partnership of others.

NLR is an active member of the International Federation of Anti-Leprosy Associations (ILEP). In 2018, our CEO was re-elected President of ILEP and we actively contribute to the International Technical Committee. Not only at the international level, but also in the countries where we work, we closely cooperate with other ILEP members in programmes such as LPEP, PEP4LEP, PEP++, and our work in Disability-Inclusive Development. In addition, we work closely with the World Health Organization and the Neglected Tropical Disease Non-Governmental Development Organization Network (NNN). The United Nations' appointment of Ms Alice Cruz as a Special Rapporteur on eliminating discrimination of persons affected by leprosy and their family members, was a big success. It pushes the fight against leprosy-related exclusion higher on the agenda of governments worldwide.

In 2018, NLR's Director of Programmes became chair of the Dutch Coalition on Disability and Development (DCDD), which lobbies the Dutch government. Together with DCDD we developed a case study showing that investing in an inclusive society creates social and economic value.

Our collaboration with Liliane Fonds has been continued and led to the launch of new programmes in Indonesia.

Lastly, we are thrilled about an initiative that was started in 2018: the Global Partnership for Zero Leprosy. This partnership brings all relevant parties working on leprosy together: national government leprosy programmes, ILEP and its members, the World Health Organization, Novartis Foundation, the academic community, organisations of persons affected by leprosy, Sasakawa Memorial Health Foundation, and many others. By joining hands, developing a common research agenda, and creating a toolbox of best practices, the Global Partnership for Zero Leprosy will help governments develop realistic roadmaps towards zero leprosy.

Thanks to...

We would like to say a massive thank you to everyone who partnered with us in 2018.

The national health programmes in the countries in which we are active:

Coordenação Geral de Hanseníase e Doenças em Eliminação Brasil, Federal Democratic Republic of Ethiopia Ministry of Health (FMOH), Ministry of Health, Community Development, Gender, Elderly and Children Tanzania, National Leprosy Control and Disability Management Programme Nepal, National Leprosy Control Programme Indonesia, National Leprosy Eradication Programme India, National Tuberculosis and Leprosy Control Programme Nigeria, Programa Nacional de Controle da Lepra Mozambique.

All government health institutions at subnational level.

Funders and collaboration partners:

Achmea Foundation, AIFO, American Leprosy Missions, Association for Reproductive and Family Health Nigeria, Association of Persons Affected by Leprosy India, CBM, CIOMAL, European and Developing Countries Clinical Trials Partnership, German Leprosy and Relief Association, Damien Foundation, DCDD, Dutch National Postcode Lottery, effect:hope, Embassy of the Kingdom of the Netherlands in Indonesia, Enablement, FAIRMED, Ethiopia Fondation Mérieux, Fontilles, Fontys, Fondation Raoul Follereau, The Global Fund, Global Partnership for Zero Leprosy, Goede Doelen Nederland, High Commissioner Australia in Pretoria, IDDC, ILEP, KIT, Karuna Foundation, KNCV, Lepra UK, Leprawinkel Deventer, Leprosy Relief Canada, Leprosy Research Initiative, Light for the World, Liliane Foundation, MORHAN, Nederlands Burgemeesters Elftal, Nepal Leprosy Trust, NNN, Novartis Foundation, NTD Support Center/COR-NTD, Partos, Peerke Donders Stichting, plan:g (Partnerschaft für globale Gesundheit), Sasakawa Memorial Health Foundation, Sightsavers, State Bank of India, Taskforce for Global Health, The Carter Center, The Leprosy Mission England & Wales, The Leprosy Mission International, The Mission to End Leprosy, WaterAid, Werkgroep '72, and the World Health Organization.

Knowledge institutions:

Airlangga University, Armauer Hansen Research Institute, Catholic University of Health and Allied Sciences Bugando, Disability Studies in Nederland, Dr. Soetomo General Hospital, Erasmus Medical Centre, Federal University of Ceará, Federal University of Goiás, Federal University of Pará, Free University Amsterdam, Indian Council of Medical Research, Institute of Human Virology, Liverpool School of Tropical Medicine, National Institute of Health Research and Development (Litbangkes), Oswaldo Cruz Foundation (FIOCRUZ), Universidade Lúrio, Universitas Indonesia, Universitas Airlangga, Vardhman Mahavir Medical College, Varanasi University.

Finances & annual accounts



Finances

2018 results in short

The annual accounts are a consolidation of NLR's annual accounts and the annual accounts of the Leprosy Research Initiative (LRI). NLR's 2018 budget is a balanced budget. In the annual accounts, however, the 2018 budget ends with a deficit of €190,000, due to the fact that the LRI budgeted a deficit for 2018.

In 2018, total consolidated income stood at €11.2 million (2017: €20.9 million), while €10.0 million was budgeted. Additional income was generated by an unexpected increase in legacies (see below). Total expenses amounted to €10.5 million (2017: €11.3 million), while €10.4 was budgeted.

The overall result equals €560,000 in 2018 (2017: €9.7 million), whereas a deficit of €190,000 was budgeted. Without income flowing into and expenses flowing from earmarked reserves and funds, the net surplus for 2018 would have been €288,000.

[See Annual accounts for more information](#)

2018 financial highlights: income

Total income above budget, but below that of 2017

Total income in 2018 exceeded budget but stood much lower than in 2017. This is due to the exceptional amount of €9.38 million that in 2017 was donated by the Dutch Postcode Lottery's Dream Fund towards NLR's project "Stop the transmission of Leprosy." The total amount for this five-year project was received and recorded as income in 2017.

Legacies

In the 2018 budget, we decided to decrease forecasted income from legacies, from an annual €2.5 million that was projected during earlier years, to €1.4 million per annum. The decision was taken to account for the risks posed by the very unpredictable nature of income collected from legacies.

Unexpectedly, in 2018 the income from legacies even surpassed the high level seen in 2017 (€3.3 million). In 2018, we collected €4.1 million from legacies. We are deeply grateful to all those who grant such sizeable donations to NLR when deciding on their will.

Fundraising in the Netherlands

In the 2018 budget, we anticipated that income resulting from our own fundraising (excluding income from legacies) would remain constant. This income type, consisting of donations by individuals, companies, and the return of goods and services, was budgeted at €2.5 million. We invested in the quality of our marketing and communication with donors. They donated more than we foresaw, resulting in an actual income of over €2.6 million in 2018.

Global Fund to Fight AIDS, Tuberculosis, and Malaria

In 2018, the Tuberculosis and Multidrug Resistant TB activities in Nigeria that in earlier years were financed by the GFATM (Global Fund to Fight AIDS, Tuberculosis, and Malaria), were carried over to Leprosy and TB Relief Nigeria (the independent NGO that was formed out of NLR Nigeria). As a result, income for that programme (2017: €1.9 million) is no longer recorded in the annual accounts of NLR.

European & Developing Countries Clinical Trials Partnership and Leprosy Research Initiative

In 2018, an amount of €3.2 million was awarded by the European & Developing Countries Clinical Trials Partnership (EDCTP) from its joint call with the Leprosy Research Initiative (LRI), which was published in 2017 (see also page 19 of the annual report). The project that was donated towards is titled PEP4LEP ("Chemoprophylaxis for leprosy: comparing the effectiveness and feasibility of a skin camp intervention to a health centre-based intervention. An implementation trial in Mozambique, Ethiopia, and Tanzania."). The multi-partner project will be implemented during a period of 52 months. The first transfer, amounting to €1.6 million, was received by NLR (the coordinator of the project) in 2018. The balance of this transfer (the amount that was not spent in 2018 or not yet transferred to consortium partners) is carried over to 2019.



2018 financial highlights: expenses

Field programmes

Direct expenses towards field programmes, excluding the GFATM (Global Fund for the Fight against Aids, TB, and Malaria), amounted to €3.3 million (2017: €4.3 million). GFATM funding, which backed NLR's TB and MDR TB activities in Nigeria for an extended number of years, was carried over to LTR Nigeria (the independent NGO that was formed out of NLR Nigeria) in 2018. Accordingly, NLR's total expenses on field programmes were reduced in 2018.

Expenses exceeded budget (set at €2.2 million) by €1.1 million. Higher income from other donors and partners could cover these expenses. Also included are expenses that were financed as investments flowing from our reserves.

Supporting projects

The expenses incurred for supporting projects were budgeted at €590,000 but equalled €1.1 million. This is explained by expenses that were financed from the investment reserve. We invested an amount of €617,000 in the NLR 2020 programme (see page 86 of the annual report) from our earmarked investment reserve. These investments are accounted for in the total expenditures on supporting projects in 2018. The NLR 2020 programme transforms our Country Offices into independent NGOs embedded in their local contexts, as an important step towards a sustainable continuation of our programmes by means of more local ownership and local governance in the countries where we operate.

Research

Research expenses include research funded by the LRI, expenses paid in support of the LPEP project, expenses flowing from the earmarked fund for the NPL-funded

project "Stop the Transmission of Leprosy," and expenses that arose in light of the EDCTP-funded PEP4LEP project, which were not budgeted. Expenses on research, therefore, amounted to €2.5 million, whereas €1.1 million was budgeted.

Other investments and expenses drawn from surplus income (above budget)

Other expenses flowing from our investment reserves, amounting to €543,000 in total, include investments to comply with the General Data Protection Regulation (GDPR, or AVG, in Dutch). Via ILEP we contributed to the launch of The Global Partnership for Zero Leprosy, we developed new fundraising programmes, and we contributed to the LepVax phase 1 clinical trials. In addition, the implementation of a financial package for all Country Offices and investments in ongoing activities to obtain ISO 9001 certification, were included. Our reserves were also drawn upon to implement the transition plans for our Nigeria and Mekong offices: both teams decided to continue part of the work as locally registered NGOs after we decided to end their structural funding in 2016. Both local NGOs will continue to implement externally funded projects, the majority of which do not have leprosy-related objectives.

Expenses drawn from earmarked funds

In 2018, we drew upon two earmarked funds:

- 2018 was the final year of NPL-funded project "These shoes are made for walking." We spent the remaining earmarked fund, at a total amount of €168,000, on the project.

- From the fund earmarked for NPL's Dream Fund project "Stop the Transmission of Leprosy," we spent an amount of €889,500 in 2018.

Communication and awareness-raising

To modernise our communication channels in the Netherlands and internationally, both our Dutch and international websites were renovated. Because of this, total expenses on communication and awareness-raising activities in 2018 add up to €555,000, while €522,000 was budgeted.

Fundraising

Expenditure on fundraising was €1.1 million, instead of the budgeted €796,000. This was partly due to investments in new fundraising software that improves communication with middle-sized and major donors, higher acquisition costs, and temporary replacement of staff on sick leave. In fact, a part of these higher expenses was financed outside the budget and drawn from the investment reserve. The expenses are accounted for as part of the realisation of 2018. In 2018, fundraising expenses amounted to 11% of total income raised, which is higher than the budgeted 8%. In 2018, the expenses on fundraising amounted to 11% of total expenses. In 2017, this percentage stood at only 6%, which is explained by the exceptionally high income collected from NPL's (Dutch Postcode Lottery) Dream Fund in that year.



Other points of interest

Consolidated annual accounts

On 1 June 2015, the Leprosy Research Initiative (LRI) was registered as a Foundation under Dutch law. The LRI is a unique model of cooperation and coordination in the funding of research. In 2015, five NGOs – American Leprosy Missions (ALM), the German Leprosy Relief Association (GLRA), effect:hope, The Leprosy Mission International (TLMI), and the Netherlands Leprosy Relief (NLR) – jointly committed to the fight against leprosy and combined their funding for leprosy-related research in the LRI. NLR's CEO Jan van Berkel acts as executive director of the Foundation. He implements the decisions of LRI's Executives Group and is supervised by NLR's Supervisory Board. As a result, LRI's annual accounts for 2018 have been consolidated with NLR's 2018 annual accounts. The consolidated annual accounts include LRI's independent annual accounts, with an explanation where the consolidated annual accounts differ from NLR's annual accounts.

Financial income and expenses

Our investment portfolio is managed by an external agency. Investment was in line with NLR's investment policy, which prescribes investments in sustainable, socially responsible, and low-risk bonds. Adherence of the investment manager to this policy is verified twice a year. In 2018, the yield on our portfolio was -1.7% (2017: 0.3%).

Unfortunately, international stock markets showed a steep decline towards the end of 2018, also affecting the market values of our stocks and bonds. The result is a loss of €213,000, against a budgeted profit of €147,000. Markets recovered early 2019, and the value lost as per 31 December 2018 was regained. The result at the end of 2017 was €75,000.

Reserves and funds

NLR's reserve policy is closely linked to long-term relationships with its partners in leprosy-endemic countries. Our partners must be able to rely on NLR and be sure that NLR can fulfil its commitments. For this reason, NLR holds an earmarked projects reserve amounting to €4.6 million.

The Continuity Reserve is an earmarked reserve that backs the organisation's continuity. NLR aims at a continuity reserve of between 0.5 and 1 times the annual costs of the work organisation. At the end of 2018, our continuity reserve held €3.8 million (1.1 times the work organisation's annual costs). As such, the amount held is in line with CBF guidelines, which prescribe a maximum continuity reserve of 1.5 times a work organisation's annual costs.

Another earmarked reserve is the Investment Reserve, which holds funds approved for internal investment in innovation, measures that increase the sustainability of our operations, staff capacity building, and transition budgets for our Country Offices in Nigeria and the Mekong Region. At the end of 2018, the earmarked Investment Reserves totalled €3.8 million.

Finally, at the end of 2018, one earmarked fund remains: for the NPL-funded project «Stop the transmission of Leprosy» totalling €7.9 million.

Looking beyond 2018

The budget for 2019 is a balanced budget. We expect income from our own fundraising activities (excluding legacies) to increase by more than €220,000 in comparison to 2018.

Income from legacies is budgeted at the same amount as 2018: €1.4 million.

On the expense side, increased income from fundraising is partly deployed to increase the funding of programmes implemented by our Country Offices. Another part will be re-invested in additional fundraising activities.

NLR Budget 2019

Amounts x €1000

This is the approved 2019 NLR budget. For the separate 2019 LRI budget, please refer to LRI’s [annual accounts of 2018](#).

Income	Budget 2019
Income from individuals	4,124
Income from companies	0
Income from lotteries	1,350
Grants from governments	0
Income from allied and joint non-profit organisations	0
Income from other non-profit organisations	4,270
Sum of the raised income	9,744
Income in return of goods and services	0
Other income	552
Total income	10,296

Expenses	
Leprosy control and disability programme activities	6,801
Coordination and medical advice	1,673
Information and awareness raising	525
	8,999
Fundraising expenses	877
Management and administration expenses	596
Total expenses	10,472

Financial income and expenses	175
Balance of income and expenses	0

Projections for 2020 and 2021, linked to NLR’s rolling Multi-Annual Strategy 2020-2022, are maintained at the level of the 2019 budget. On the income side, we expect a stabilisation of income from our own fundraising and legacies; on the expenses side, we also expect a stabilisation of the annual budget.



Colophon

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

IBAN: NL84 INGB 0000 050 500

info@leprastichting.nl
www.leprastichting.nl
www.nlrinternational.org

www.facebook.com/leprastichting
www.twitter.com/leprastichting
www.youtube.com/user/leprastichting

Design: BEELDR
Copy: NLR
Photography: NLR, Tom Bradley, LegHetVast, Marcelo Londoño
Sasja van Vechgel

until
No Leprosy Remains
