



Annual Report 2020

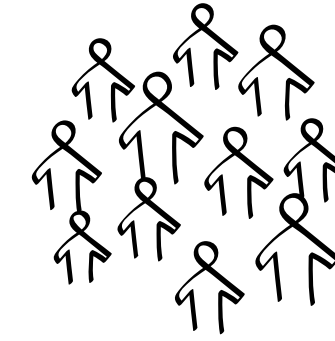
# Overcoming Challenges

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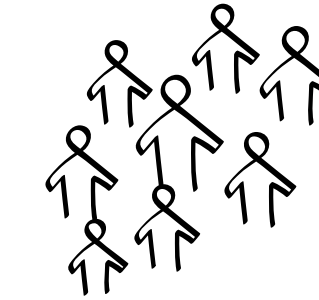
# Working together to fight leprosy

1985



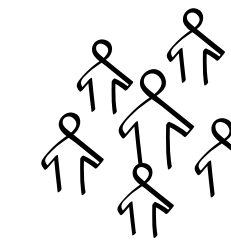
550,224\*

1995



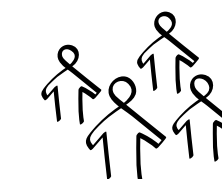
529,376\*

2005



296,499\*

2019



202,185\*



## Towards a world free of leprosy and its consequences

\*number of new leprosy patients detected worldwide

Source: World Health Organization



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Vision, mission, story



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Zero Transmission



Zero Disability



Zero Exclusion



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'Stop the transmission of leprosy' project in Brazil and India



Start Ready4PEP project



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Staff composition



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Financial Highlights 2020: income



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NLR Budget 2021



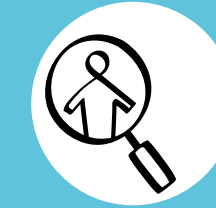


# 2020 in brief

## until No Leprosy Remains

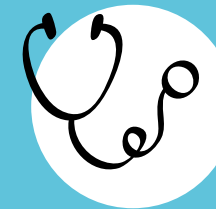
In 2020 flexibility and creativity were needed in adapting to constant changes and new situations for individual staff as well as the organisation as a whole. Despite the COVID-19 pandemic, our donors showed that altruism is very much alive and continued to support NLR's initiatives because they believe in our purpose. The fight against leprosy is one with many obstacles, but together with our donors, partners, staff and other supporters we can overcome the challenges we face.

### Zero Transmission



**24,176**

New leprosy patients detected



**4,384**

Health staff trained on leprosy



**54,027**

Persons who received SDR-PEP

### Zero Disability



**1,936**

Health staff trained on prevention of disabilities

### Zero Exclusion



**2,487**

Local actors better voicing concerns and needs



**2,284**

Persons affected with improved socio-economic situation



**2,350**

Health staff sensitised on stigma

## Our highlights

### Launch 'Stop the transmission of leprosy' in India and Brazil

NLR aims to reach 800,000+ contacts of persons already diagnosed with leprosy.

### Start of ReadyPEP project in Mozambique and Nigeria

Governments of both countries have shown enthusiasm and willingness to work together with the partners in this project.

### Guides on Stigma and Mental Wellbeing

Increase awareness and understanding and help to strengthen the technical and interpersonal skills required to handle stigma and its repercussions.

### Leprosy e-learning modules

Designed for health supervisors to acquire accurate diagnostic skills and provide adequate understanding.

### SDR-PEP animation

"The message is so clear: This is the problem, and this is the solution."



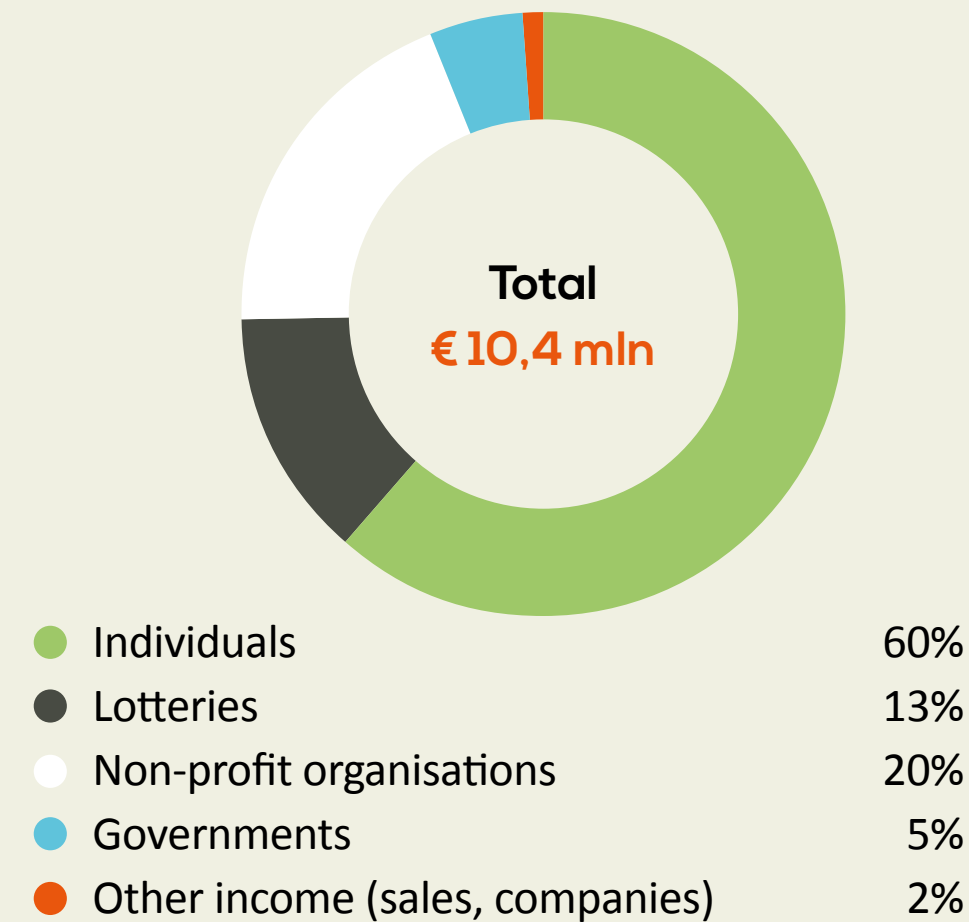
# How did we spend our money in 2020?

In 2020, we received a total of €10,4 million income. We spent €9,1 million on our objectives, which is 81% of our total expenditures. The continued support of our institutional and individual donors is vital as it enables us to diagnose, treat and cure persons affected by leprosy across three continents. Throughout the Netherlands, we received support from 44,996 donors and around 350 volunteers. NLR receives an annual contribution of €1,350,000 from the Dutch Postcode Lottery and its participants. This is much appreciated, particularly as it is unearmarked income which we are free to allocate where and when it is most needed.

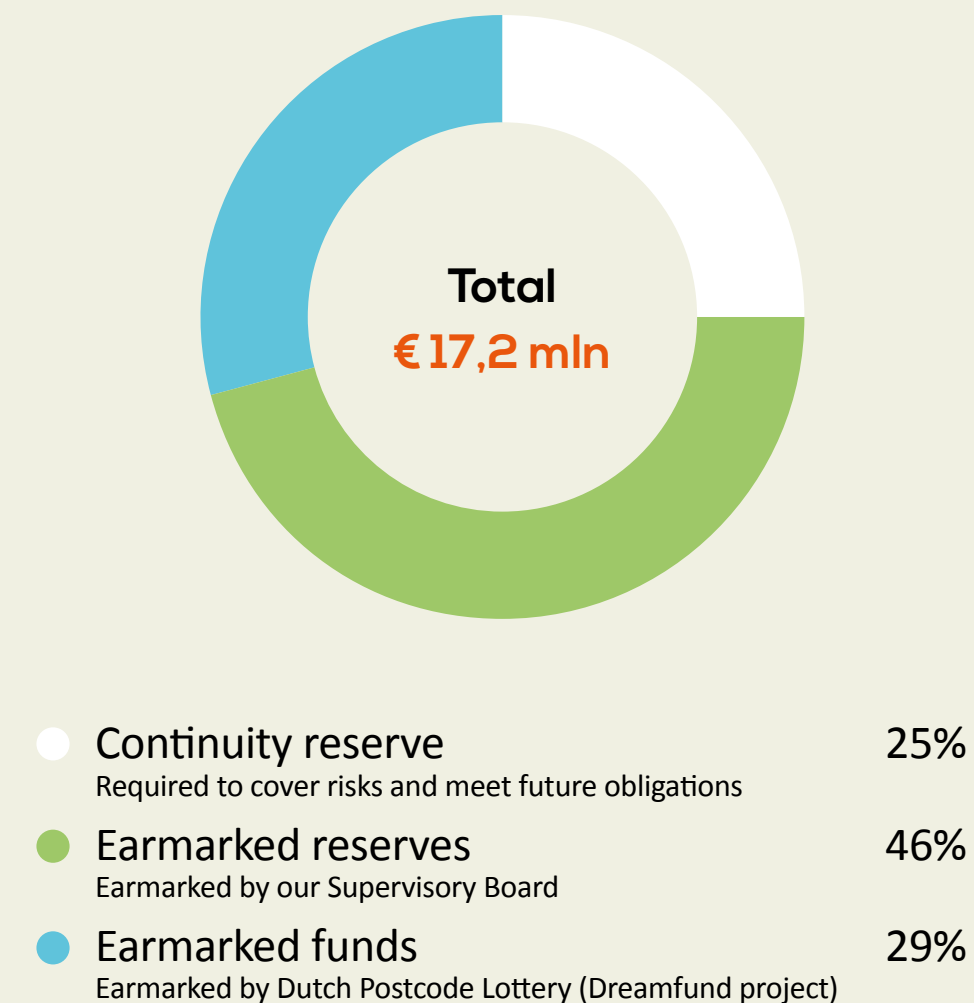
Other details concerning our income and expenses are shown in the Annual Accounts.

**Annual accounts**

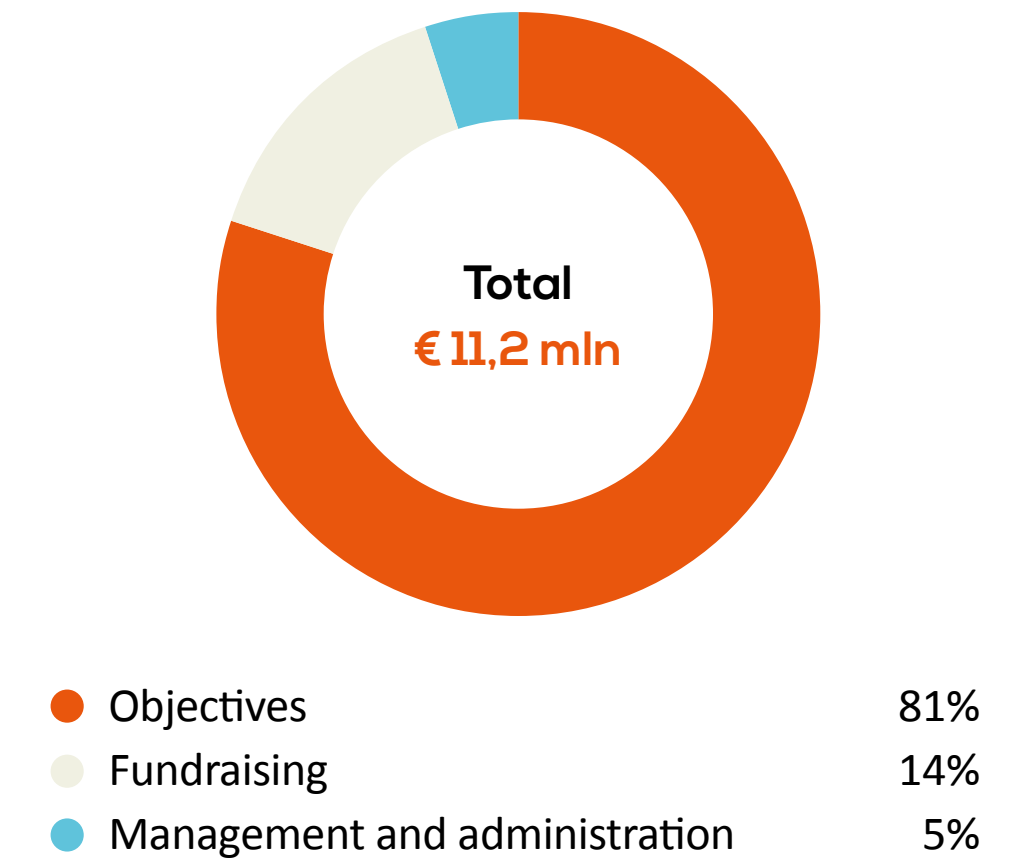
## This was our income in 2020



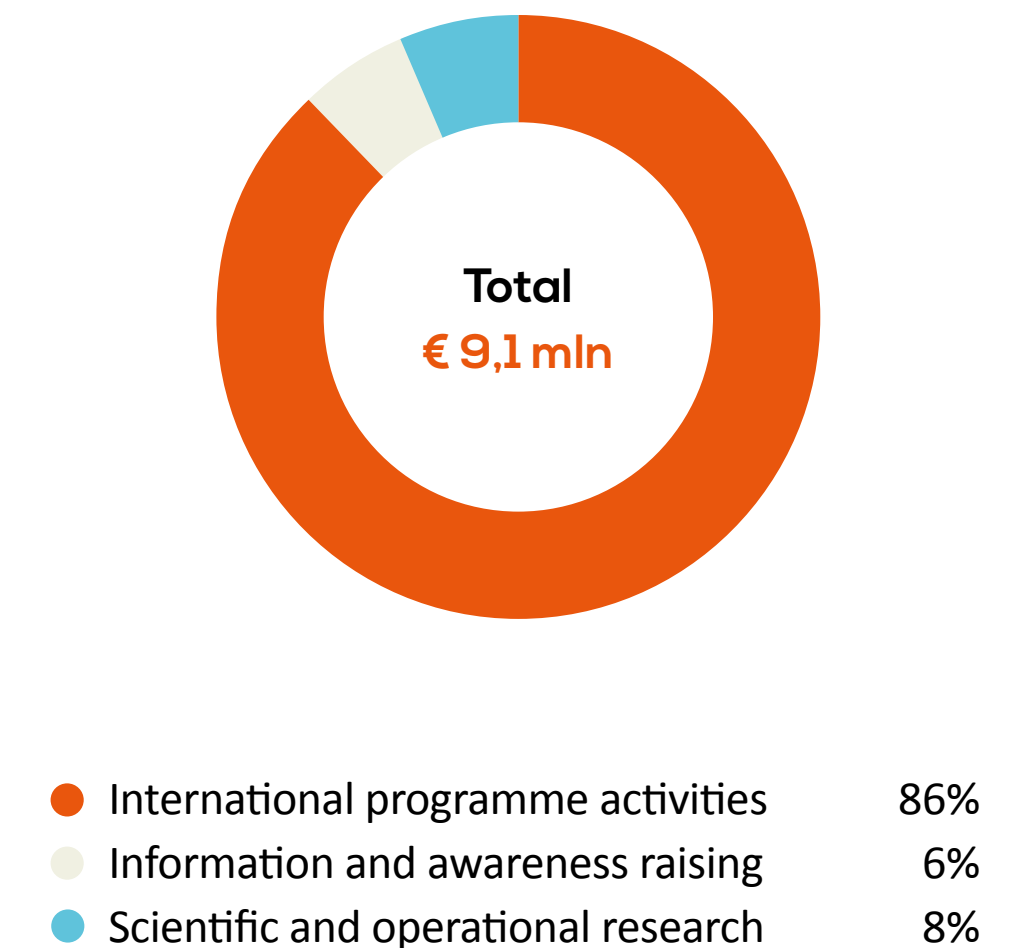
## In support of our mission, these were our reserves and funds in 2020



## This is what we spent in 2020



## This is what we spent on our mission in 2020





# SWOT Analysis

## Our organisation

### Strengths

- Track record of over fifty years in evidence-based leprosy programmes.
- Global forerunner in innovative, scientific leprosy research
- Leading partner in many local and global networks and partnerships related to leprosy and other Neglected Tropical Diseases (NTDs).
- Strong reputation in the leprosy and NTD sector.
- Presence in countries with highest number of leprosy cases.
- Development and implementation of innovative approaches.
- Strong technical expertise combined with programmatic know-how.
- Diverse staff including new generations.
- Loyal individual donors in the Netherlands.

### Weaknesses

- Difficult to attribute parts of our work to NLR as a result of working in partnerships.
- Limited presence in leprosy endemic countries.
- Lack of focus and coordination in advocacy activities.
- Small team in relation to an increasing number of activities.
- Inconsistent use of several brand names.
- Low brand awareness outside the 'leprosy world'.
- Insufficient visibility in the media.

## Our environment

### Opportunities

- Growing number of private funders/donors.
- Growth of public-private partnerships in the field of NTDs.
- Organisations in related fields show interest in NLR knowledge and best practices.
- Increasing attention for leprosy at the World Health Organization.
- eHealth and mHealth (Mobile Health) solutions.
- Promising research in the field of leprosy prevention.
- The fact that leprosy is a preventable and curable disease is interesting for donors.
- Increased global awareness of the need for strong health systems due to COVID-19.

### Threats

- Decline in technical leprosy capacity worldwide: retiring leprosy doctors and health workers.
- Decreasing awareness of leprosy among researchers and health workers due to its elimination as a public health problem in many countries.
- Limited governmental resources in endemic countries, competing demands of different NTDs.
- Diminishing loyalty with organisations of members, donors or volunteers.
- Increasing legal and administrative burdens for international NGOs in some leprosy endemic countries.
- Highly competitive fundraising market for individual donors and institutional grants.
- Backlogs due to COVID-19 and restrictive measures affecting beneficiaries.
- Increasingly critical attitude towards NGOs.
- Global political instability.



# We are NLR



# 2020 in review

In recent years we at NLR have often cited an old African proverb to describe our way of working: *“If you want to go fast, go alone. If you want to go far, go together”*. In 2020, working together proved yet again to be the most effective way to support persons affected by leprosy. Another African proverb summarises the unprecedented challenges of 2020: **“Smooth seas do not make skilful sailors.”** Flexibility and creativity were needed in adapting to constant changes and new situations for individual staff as well as the organisation as a whole. In a turbulent year, NLR proved to be a resilient, forward moving organisation across the board.

Since 1967, NLR has devoted itself to fighting an ancient disease that is still present across the world. Understanding global trends is therefore crucial. We live in a time of multiple, evolving and mutually reinforcing shifts in geopolitics, demographics, climate, technology, society and the economy that all generate both threats and opportunities for NLR’s work.

There is low awareness of leprosy in particular and neglected tropical diseases in general, even though these diseases affect around a billion people worldwide. This results in stigma and discrimination towards those affected and shrinking resources to provide adequate support. NLR faces highly complex challenges with global implications, especially when it comes to income and gender inequality, and a crowded and competitive ‘marketplace’ for NGOs.

2020 threw even more challenges into the mix. With COVID-19, NLR faced a situation we had no control over. As demand for health and social services increased, NLR’s projects were derailed and field workers grounded due to government measures, resulting in substantially fewer opportunities to implement programmes and projects. However, we did have control over how we adapted to the situation. We took advantage of opportunities in digital solutions and the broader interest in and knowledge of infectious diseases due to COVID-19. Our first priority was the health of our colleagues and the people in the communities where we work. Mobile phones, SMS, WhatsApp, local radio were used to reach persons affected by leprosy with information about preventing the spread of COVID-19. NLR provided emergency aid and we intensified our lobby and advocacy to ensure those affected by leprosy received the governmental and social support they needed.

## Overcoming challenges

If there is one positive affirmation for NLR resulting from the COVID-19 pandemic in 2020, it is that altruism is very much alive. Our donors continued to support NLR’s initiatives because they believe in our purpose. NLR’s challenge is to involve them in ways that meet their evolving needs. The fight against leprosy is one with many obstacles, but together with our donors, partners, staff and other supporters we can overcome the challenges we face. Now more than ever we invite you to help in any way you can: donate, support, share our story, collaborate with us and invite us to join you. This is how we will support persons affected by leprosy until No Leprosy Remains.

## Organisational development

In order to have the best structure to achieve our mission and for optimal delivery of our leprosy work now and in the future, NLR is transitioning from an organization headquartered in the Netherlands to an Alliance with locally established member NGO’s. This important development of NLR is strongly supported and monitored by the Supervisory Board. This year the (former) country offices in Indonesia, India and Nepal took important steps in the last phase of this process.

## A transition of directors

2020 was Jan van Berkel’s final year as NLR’s CEO. We are very grateful for his inspiration, guidance and energy over the last 12 years before his retirement. During his tenure Jan realised the Leprosy Research Initiative, served as President of the International Federation of Anti-Leprosy Associations (ILEP) and laid the foundations for re-shaping our organisational structure into the NLR Alliance. Jan worked in NGOs for many years of his career. In 1995 he co-founded Goede Doelen Nederland, the trade association of recognised charities in the Netherlands, where Jan still serves as Chair of the Board. His lifelong work for NGOs has been recognised by King Willem-Alexander of the Netherlands. During his online farewell event, Jan received the Royal Award of Officer of the Order of Oranje-Nassau from his city mayor, a great honour for his achievements.

Linda Hummel was appointed as the new director of NLR and started on 1 January 2021. Linda has years of experience in innovative international organisations; first in the private sector, then later in international development cooperation.



**Bram van Ojik**

Chair of the Supervisory Board



**Linda Hummel**

Chief Executive Officer



# Vision and Mission

In the poorest regions of our planet people still suffer from an ancient disease. Despite incredible medical evolution, every year over 200,000 people are diagnosed with leprosy, including almost 20,000 children! Leprosy can cause disabilities and creates a vicious cycle of poverty, stigma, unemployment, social exclusion, and mental health problems. For NLR it is unacceptable that this disease still prevails in 2020, which is why we continue to work tirelessly and relentlessly, even in the midst of a pandemic caused by another infectious disease.

## Vision

**A world free of leprosy and its consequences**

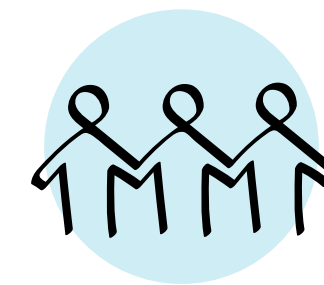
This is the vision that drives our organisation and inspires us to serve those affected by leprosy around the world.

## Mission

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

## NLR – until No Leprosy Remains

In 2019 we changed the meaning of the abbreviation NLR from Netherlands Leprosy Relief to until No Leprosy Remains. This new name reflects our core mission, and also the fact that NLR transitions into an alliance with international NGOs. A link to the Netherlands in our name is therefore no longer representative. Now, all NLR Alliance members are united by a strong brand, mission and vision under one name, while at the same time retaining the well-known abbreviation: NLR.



**“All NLR Alliance members are united by a strong brand, mission and vision under one name.”**

## NLR Alliance: moving forward

In 2020, NHR Brazil and NLR Mozambique took preparatory steps that are still ongoing for the two-year transition phase. This includes establishing a national NGO and forming a supervisory board.

In 2020, NLR Nepal, NLR India and NLR Indonesia were already in their first year of a two-year transition period. All these countries have signed the Alliance Membership agreements. After two years the Board of each NLR national NGO and the Supervisory Board of NLR assess the readiness of the national NGOs for the final handover of responsibilities, power and assets by NLR. Before this happens, a transition audit will be carried out in 2021. The transition period may take longer if after the two transition years the parties involved conclude that the admission requirements mentioned in the agreements have not yet been met.

We also welcomed two Associate Members in 2020. At the end of 2016, NLR had to stop structural financial support for its former offices in Vietnam and Nigeria. Both offices continued as independent NGOs and NLR helped both organisations to grow. This led to the establishment of the Research Center for Inclusion (RCI) Mekong and LTR (Leprosy and TB Relief) in Nigeria. Now, both organisations have joined the NLR Alliance as Associate Members with specific agreements.



# Where we work

## IN 2020

New leprosy patients detected in NLR intervention areas	24,176 (1,529 were children)
Endemic areas with PEP support	158
Contacts received SDR-PEP	54,027
Health staff trained on leprosy, prevention of disabilities and stigma	8,489
Local actors voicing concerns and needs of people affected by leprosy	2,487
Persons affected by leprosy with improved socio-economic situation	2,284

### Brazil

673 (15)
2
159
1,067
10
34

### the Netherlands

### Nepal

421 (5)
9
8,763
295
2,295
55

### Mozambique

1,175 (136)
7
459
27
1,224

### India

12,677 (538)
119
(To be confirmed)
3,441
130
924

### Indonesia

9,230 (835)
21
45,105
3,227
25
47

Read about our indicators →

Data from India are preliminary due to reporting delays caused by the COVID-19 pandemic



# Leprosy: still a pressing matter

Leprosy is most prevalent in poverty-stricken areas in communities that have difficult access to proper health care. There is a long incubation period before symptoms become apparent. Even then, leprosy is very easily misdiagnosed. In 2019 the number of new leprosy patients reported globally was 202,185\*. The geographical distribution of leprosy is uneven, with 80% of the world's leprosy patients living in three countries: India (57%), Brazil (14%) and Indonesia (9%). Of the new patients that were detected across the globe in 2019, 7% were children and 5% had grade two disabilities at diagnosis, both indicators of ongoing transmission and of late diagnosis. In addition, these percentages indirectly provide information about community and health workers' awareness of leprosy and the quality of leprosy services.

The number of newly detected patients is decreasing slightly every year. However, the problem with the official figures is that they only reflect patients who sought medical assistance and were recorded in the national data. They do not include those who either have not yet manifested symptoms or were misdiagnosed. These people could infect others for years before leprosy is diagnosed. Furthermore, the official numbers do not include the close contacts of leprosy patients who run the risk of contracting the disease.

An unfortunate consequence of decreasing official numbers is that fewer clinicians learn to diagnose leprosy, while clinical recognition is the starting point for treatment. The capacity and capability for timely detection, diagnosis and the current treatment of leprosy are decreasing year by year, leading to multiple incorrect diagnoses before people start treatment. That delay is critical: the longer the infection remains untreated, the greater the chance that a person will develop lasting nerve damage and irreversible physical impairment. Research by the Erasmus University Medical Centre and NLR shows that even by modest calculations millions of people are still at risk. It is practically impossible to eliminate a disease by reacting only to new cases. This is why NLR is aiming to run ahead of the official numbers and invest substantially to stop transmission and integrate preventive treatment in national leprosy programmes.

NLR develops its policies and programmes in collaboration with its partners (WHO, Ministries of Health and Disabled People Organisations) in accordance with the Sustainable Development Goals (SDGs) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Together they aim to combat neglected tropical diseases (NTDs) and their consequences, and to contribute to poverty reduction, promotion of human rights and social inclusion of persons affected by leprosy and those with disabilities.

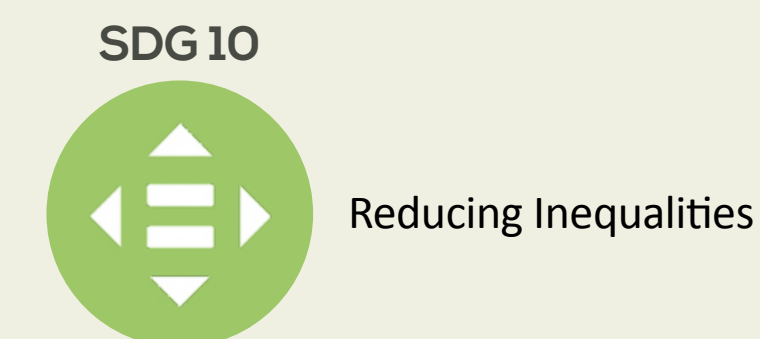
## Obstacles during the COVID-19 pandemic

The spread of COVID-19 and the measures which governments have subsequently taken have impacted lives across the globe. Of course this has also affected our work in the countries where we are active: India, Indonesia, Brazil, Nepal, Mozambique, Nigeria, Tanzania, Ethiopia and the Netherlands. Some of these nations were severely impacted by the virus. The local governments have taken measures of different proportions to stop the spread of the virus, depending on the local situation. These measures have disrupted daily life and had far-reaching consequences for the implementation of our ongoing projects. As our teams initiated COVID-19 information and education campaigns in their working areas and assisted in emergency aid for our beneficiaries, their regular work suffered delays and backlogs.

The current health crisis reveals social inequalities with greater clarity. Especially the most vulnerable often feel insecure about the prevention of infection. Isolation and physical distancing further fuel feelings of exclusion. Moreover, government resources normally allocated to leprosy control were being spent on COVID-19 control.

\* The official number of new cases is reported each year by WHO around August/September. Therefore, we cannot yet provide the official numbers for 2020. The number of newly detected patients will be lower in 2020, because of the COVID-19 pandemic negatively impacted case finding.

Our work contributes to at least three United Nations Sustainable Development Goals (SDGs):





## Importance of research and innovation

New preventive interventions have been developed, such as contact screening combined with the provision of a single-dose of rifampicin as a post-exposure prophylaxis ([SDR-PEP](#)). SDR-PEP reduces the risk of developing leprosy in contacts by nearly 60%. To interrupt transmission and reduce the number of new cases to zero this new strategy needs to be implemented. This should be achieved by targeting people most at risk of developing leprosy: the contacts of new leprosy patients. The LPEP project was a study coordinated by Novartis and implemented by NLR in collaboration with Ministries of Health, other leprosy NGOs and scientific partners including the Erasmus University Medical Centre. The results of this programme published in 2020 showed that this intervention is feasible: it can be integrated into existing leprosy control programmes. If scaled up globally it has the potential to almost eliminate leprosy in a single generation.

NLR is conducting a research project into a new and more powerful preventive chemotherapy regimen for leprosy that is expected to be 80-90% effective. This new and enhanced regimen is called PEP++ and is combined with innovative approaches to intensify the case detection of leprosy. The effectiveness of the new regimen is being investigated in India, Brazil and Indonesia in the 'Stop the transmission of leprosy' project funded by the Dutch Postcode Lottery. In 2020 the project was officially launched in India and Brazil.

Some major priorities for research in immunology of leprosy include diagnostics for detection of early cases, relapses, drug resistance and viability of *M. leprae* (the bacterium that causes leprosy). More importantly, no leprosy specific vaccine is available yet. A vaccine would be of great value in breaking the chain of transmission. NLR therefore supports the clinical trial for a leprosy vaccine led by American Leprosy Mission.

Leprosy is not only a medical problem, but also a social disease. Leprosy-related stigma is perhaps the oldest form of disease-related stigma known to humanity. Besides medical solutions to improve prevention and treatment, NLR also focuses on research on stigma and mental wellbeing. Evidence-based information and recommendations are developed and promoted to have a positive impact on community behaviour and to raise awareness. The goal is that these are adopted by policy makers, health workers and community members. In 2020 NLR contributed significantly to the development, publication and promotion of the Guides on Stigma and Mental Wellbeing, a co-production of the International Federation of Anti-Leprosy Associations (ILEP) and the Neglected Tropical Disease NGO Network (NNN). These provide best practice information, tools and recommendations from various disciplines on the causes and manifestations of stigma, how to assess the experience of stigma and mental wellbeing, and how stigma can be reduced.

## On the road to zero leprosy together

NLR is a strong believer in collaboration. NLR can only fulfil its mission to stop the transmission of leprosy in partnership with others: members of the NLR alliance, national governments, other NGOs, researchers and donors. Cooperation is the foundation of our work. For example, in 2020 NLR and NLR Nepal teamed up with AIM Initiative/ALM to map persons affected by leprosy in Nepal to better target new case detection initiatives and SDR-PEP implementation. A useful best practice will be developed with tools, protocols and flow charts that will be made available globally for use by Health Ministry Leprosy Programme Managers and NGOs when implementing SDR-PEP. Additionally, tools for data management, data collection and data analysis will be shared to help others carry out mapping themselves.

In 2020, NLR and NHR Brazil have also initiated collaborations with new partners. NHR Brazil is working with UNESCO to implement strategies to combat stigma among persons affected by leprosy and other Neglected Tropical Diseases.

NLR is an active partner in international networks such as the Global Partnership for Zero Leprosy (GPZL) and the International Federation of Anti-Leprosy Associations (ILEP). In 2020, NLR's CEO was president of ILEP until October and Chair of the Executive Group of the Leprosy Research Initiative. NLR's Medical Director chaired ILEP's Technical Committee. Within these and other networks we make a significant impact towards achieving our mission.



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



# Our Donors





# Working together in challenging times

Due to the COVID-19 pandemic and the subsequent national measures taken and travel restrictions, 2020 was a challenging year. Still, we managed to do as much as we could to make sure the diagnosis, treatment and care of as many persons affected by leprosy as possible could continue across the three continents. We also continued our commitment to combat discrimination and promote inclusion for those affected by leprosy, despite demanding working conditions. Our global efforts are only possible because of the ongoing generous and essential donations from our individual and institutional donors, and with the help, commitment and collaboration of ambassadors, volunteers, partners and other organisations. It is by working together, even in challenging times, that we can truly make a difference and continue until No Leprosy Remains.

## The impact of COVID-19

Despite of the COVID-19 pandemic our donors remained loyal and continued to support us in our battle against leprosy in 2020. This enabled us to support persons affected by leprosy who are especially vulnerable at this time. Not only do they have to deal with the disease itself, but also with the hardships that came with the pandemic.

Due to the national lockdown in the Netherlands, we were unable to recruit new donors through door-to-door marketing. After a few months postponement, we were able to catch up with our donor recruitment by the autumn. Face-to-face donor events were cancelled, so instead we called many of our donors by telephone to thank them for their support.





# Cooperating with institutional donors

Partnerships with foundations, governments, multilateral organisations and other international NGOs are crucial to reach zero leprosy. The financial resources raised through these institutions help NLR create long-term impact. And as partners with expertise and networks they contribute to our mission in a broader way. In 2020 we continued working with dedicated partners such as the European and Developing Countries Clinical Trials Partnership (EDCTP), Netherlands Embassy in Indonesia and the Dutch Postcode Lottery. At the same time, we are delighted to have set up a new partnership with UNESCO in Brazil and expand our cooperation with new funds from Leprosy Research Initiative, The Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD) and Novartis Foundation.

NLR is also proud to have taken on an active role in the development of a bold \$100 million project which reached the Top 100 of the highest-scoring proposals in the prestigious MacArthur 100&Change Competition. Due to the excellent coordination of the

Global Partnership for Zero Leprosy, the whole sector has shown great potential to take large strides to raise funds for zero leprosy, together. Similar fundraising approaches will be replicated in the future.

In addition, the International Office concentrated in 2020 on strengthening Alliance members' capacity in institutional fundraising. Alongside concept note writing, we trained them on donor mapping, donor cultivation and coordination of the proposal development phase. This has resulted in country offices being able to create a more solid base with a clearer fundraising strategy.

## The Dutch Postcode Lottery

The Dutch Postcode Lottery is one of NLR's most important partners. We have been a beneficiary for 25 years, receiving an annual contribution in 2020 of €1,350,000. As unearmarked income we are free to allocate it where and when it is most needed. We greatly appreciate the commitment of the Dutch Postcode Lottery in their ongoing contribution to our mission to

fight leprosy and to raise awareness of our cause among a broader public through various communication channels, including national television.

## Dream Fund

In addition to this annual contribution, in 2017 we received €9,375,000 from the Dutch Postcode Lottery Dream Fund that fully funds our five-year long **Stop the transmission of leprosy!** research project. This ground-breaking project seeks to halt the transmission of leprosy with an enhanced preventive treatment in India, Brazil and Indonesia (together they account for 81% of all new leprosy cases). We conduct research in two districts in each of the three countries. The project involves providing the closest contacts of those affected by leprosy who were diagnosed over the last five years with an enhanced dose of antibiotics. In addition, more distant contacts receive a single dose of SDR-PEP to reduce their risk of developing leprosy. For more information about this project please see [page 30](#).





# Dutch Postcode Lottery Interview



We asked Dorine Manson, managing director at the Dutch Postcode Lottery, about her perspective on their long-standing collaboration with NLR.



**The Postcode Lottery has been supporting NLR since 1996. What are the most important success factors behind this wonderful, long-term collaboration?**

"Thanks to its participants, the Lottery has been able to give an amount of money to NLR each year that has no spending restrictions, because we think the charity knows best how to achieve maximum impact. NLR has certainly made the most of this partnership: great results have been achieved and you have also been able to demonstrate this to our participants. And the collaboration has always been a very pleasant one."

**What are the similarities between the mission of the Postcode Lottery and that of NLR?**

"Our mission is to work towards a green and just world, and to achieve this we need civil society organisations. The best version of that world does not go together with disease and exclusion. NLR's mission is a world without leprosy and to combat exclusion based on disabilities. So, both missions are seamlessly aligned, especially in the area of justice."

**In 2017 NLR received €9.3 million from the Dream Fund of the Postcode Lottery for the project 'Stop the transmission of leprosy!' What was so special about this project for you to support it with such a tremendous amount?**

"In this project, aspects such as innovation and thinking big play a big role. The aim of the project is to treat 500,000 people preventively in three countries with a new combination of medicines in order to drastically reduce the number of infections. This shows ambition and vision over the long term. And that is exactly what we have in mind when we award the Dream Fund."

**With regard to our cooperation, what would you like to see in the years to come?**

"We very much hope that we can continue to be equal partners who communicate well with each other in an open and transparent way. This is already going very well, and we would like to continue this."





# Individual donors & Communications

## Donors are at the heart of our organisation

Our work for persons affected by leprosy is only possible thanks to the thousands of people who are willing to support us. Individual donors are therefore at the heart of our organisation. They are highly valuable to us and we aim to tailor our communication to their needs. We do this by adapting information to their wishes and preferences. We are transparent about our spending and accountable to those who entrust their donations to NLR.

## Growing number of committed donors

In 2020, 44,996 individual donors in the Netherlands donated a total of €6,3 million of which €3,7 million from legacies. This is an increase of 44% compared to the previous year, when we received a total of €4,4 million. To achieve zero leprosy, ongoing support of committed donors is needed over the next decade. We therefore invested more than in previous year in the recruitment and involvement of additional donors in 2020. By the end of 2020, the total number of committed donors was 13,094 (an increase of 25% compared to 2019). This increase creates greater certainty around the amount of donations we can expect in years to come. The number of incidental donors decreased by 8,667 to 23,111 (down 27% from 2019). Some incidental donors decided to support NLR more frequently and are now considered to be committed donors. Others unfortunately passed away.

## Responding to the needs of our donors

We are committed to providing our donors with high quality information and service. Four times a year each donor receives a copy of De Klepper, our donor magazine, which includes stories and interesting articles about leprosy and those affected by it, our projects and our results. Our service desk is ready to answer questions personally and to resolve any complaints over the telephone or by email. Unfortunately, all face-to-face donor meetings which allowed for personal contact and for sharing more background information about our projects were cancelled because of COVID-19. Instead, we called many donors on several occasions and also organised a special ‘Thankathon’ event at the Amsterdam office, with colleagues from all departments, just before the first lockdown started. Together we called 250 individual donors to thank them for their support and commitment to our work. This unexpected call was very much appreciated.

To better understand our donors’ needs, we conducted a donor research project in 2020 which provided insights into donors’ perspectives on our way of working, communications and how to further improve our donor service. We service. We implemented a new CRM system which enables us to focus even more on our customers’ needs.







## Legacies

Our donors are very loyal and they are committed to our work. A good example of this is the growing number of people who are willing to include us in their will. We consider legacies to be special gifts and we feel honoured that many donors trust us to spend their legacies for the benefit of persons affected by leprosy after they have passed away. We want to live up to that trust by providing relevant information about results and ground-breaking developments, and also by enabling persons affected by leprosy to share stories about what the support of donors in the Netherlands means to them.

## More donors, more impact

To make a substantial impact, we rely on the support of our individual donors. For this reason, in 2020 we continued to invest in recruiting new donors in different ways, such as door-to-door, telemarketing and online recruitment. As a result, the total number of individual donors increased for the first time in many years from 43,116 (2019) to 44,996 (2020). To welcome our new donors and to make them feel appreciated, we welcome them with brochures, email and thank you phone calls.

## Personal recruitment

Following a very successful test in 2019 we continued to recruit new donors door-to-door in 2020. Despite a pause of 14 weeks due to COVID-19 we were still able to reach our objectives for 2020 and as a result we welcomed almost 2,300 new committed donors. Because of these positive results we will continue this method of personal recruiting in 2021.

## From incidental to committed donors

Many people support us with a one-off donation. Since structural donations provide more financial certainty for our leprosy programmes, we invested in telemarketing to reach out to these donors about supporting us monthly. In this way 1,038 incidental donors became committed donors. In addition, another 270 structural donors raised the amount of their donations, while 42 donors who had stopped their donations restarted them.

In 2020 telemarketing legislation changed. Dutch NGOs are no longer permitted to directly contact persons in their database who have not made a donation in the previous 36 months. This provides us with an additional challenge when it comes to telemarketing.

## Complaints

We consider a good relationship with our stakeholders and donors to be of the utmost importance. Complaints and remarks are seen as valuable feedback and we strive to address them with due care and with a view to finding an adequate solution. A new complaints policy was implemented that facilitates a more timely and appropriate monitoring and response to complaints.

In 2020 we received a total of eight complaints, with the majority expressing concerns around door-to-door recruitment. All complaints were promptly dealt with according to our complaints policy, and depending on the nature of a complaint, either explained or investigated.



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



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

Wil Ottens, individual donor



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

Sipke van Belle, individual donor



“I am happy that I can do something for the people affected by leprosy.”

Peter Euser, Ambassador, volunteer campaign organiser over many years



“Leprosy is such a terrible disease. If we can help NLR a little by collecting old paper, we are very happy to do so.”

Mrs Lammers, volunteer and organiser of a monthly old paper collection campaign in her village.



“There is no need for children to suffer from something that should be long gone. Together with all the other recruiters and donors I want to ensure that we can cross leprosy off the disease list.”

Lisa Janssen, door-to-door recruiter



Huub Stapel, celebrated actor and NLR Ambassador

“I was very young when I first heard stories about leprosy. These stories made a deep impression on me and I have never forgotten them. When I went on a trip to India for NLR two years ago and visited a leprosy colony there, all those stories came alive. India is the country with the most persons affected by leprosy in the world. As a patient, life in India is far from easy: not only are you discriminated against but often hidden

away in a colony. Life is also intense for children of persons affected by leprosy. They have fewer opportunities, even if they do not even have leprosy themselves. Being a child of person affected by leprosy is a cause of shame in India. NLR is working hard to stop leprosy through information, treatment and early detection of infections, and I am happy to contribute to that.”



Rasing awareness for leprosy

For many Dutch people leprosy is an issue far from home and a disease of the past. By making clear that large numbers of people still have to deal with the devastating consequences of the disease every year and that a world without leprosy is a realistic goal, we underline that leprosy is an urgent issue.

It is important to connect people who support our fight against leprosy and those who are affected by leprosy. In 2020 emotional storytelling by personal videos, images and written stories was an important way to deliver this message. We used storytelling to make a disease that prevails far away relatable to people in the Netherlands. Our donor magazine De Klepper appears quarterly and we send a digital newsletter six times a year. These are the main ways of informing our donors. In addition, on World Leprosy Day (31 January), we drew worldwide attention to leprosy and the impact of discrimination and stigma on persons affected.













Brand awareness in the Netherlands

To differentiate ourselves from other charitable organisations, brand awareness of the Leprastichting, as NLR is known in the Netherlands, is important. Now more than ever, we need to demonstrate the uniqueness, effectiveness and relevance of our cause and raise awareness among the Dutch population. To achieve this we developed a new brand strategy in 2019. Evaluating the impact of this new approach is key. Therefore, we will conduct a study every two years. In 2021 we will once again reflect on the results of our efforts and adjust our strategy accordingly.

In December 2020 our cooperation with Libelle and Margriet magazines resulted in a ‘charity special’ of 16 pages about the work of three NGOs focused on children: Leprastichting, Make-A-Wish and Plan Nederland. This special cooperation showcased our organisation and work to 1.4 million (mostly female) readers in the Netherlands, which made a positive contribution to our brand awareness.

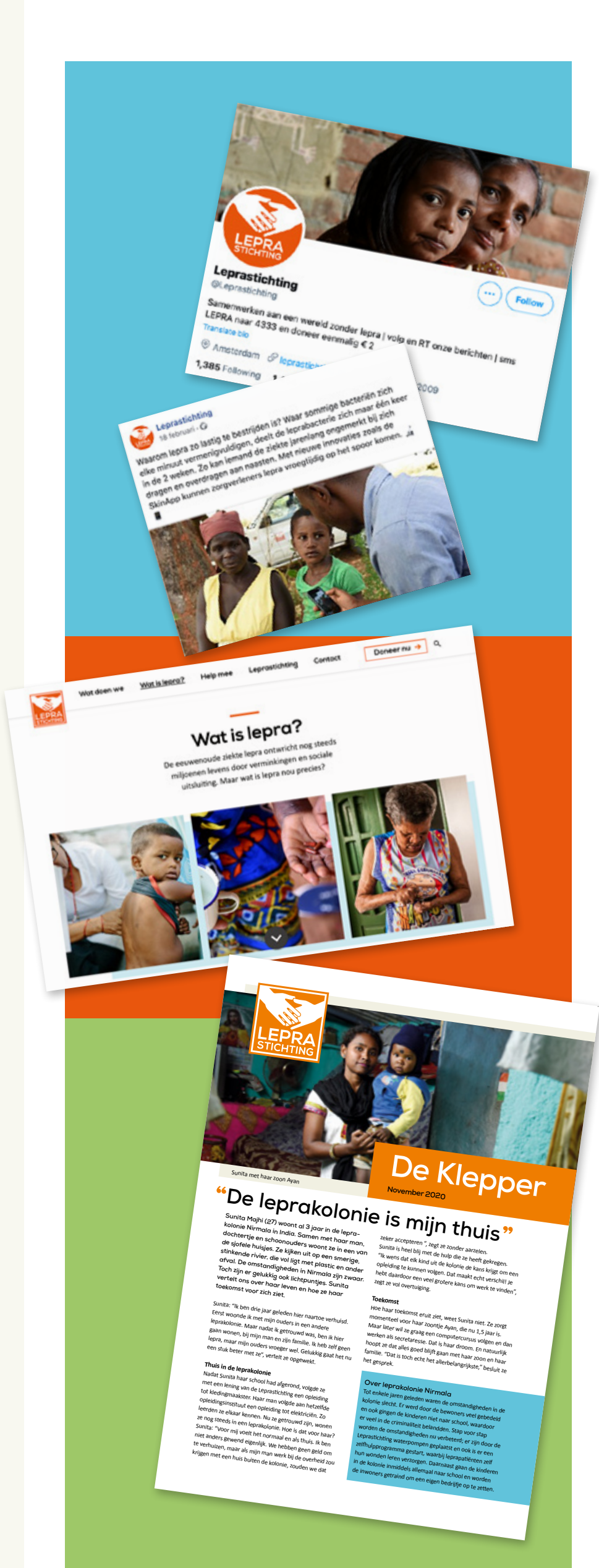
In 2020 we issued two press releases to share important news. The first covered World Leprosy Day and the second focused on the appointment of our new CEO Linda Hummel. These press releases had a joint reach of 700,235 people.

Leprastichting:  
Online channels in 2020

	2019		2020
 Followers on Facebook	1.958		2.062
 Followers on Twitter	1.403		1.425
 Followers on LinkedIn	0*		580
 Unique website visitors	81.653		101.302
 Youtube views	30.795		163.100
 Newsletter subscribers	Dec 4.556		Dec 4.400

Results Leprastichting/Dutch website and social media

\*There are no results available for our LinkedIn account in 2019.

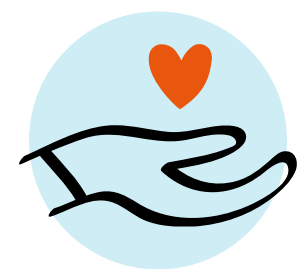




## Campaigns in the Netherlands

To improve our brand awareness we ran two online campaigns. In May and June of 2020 the first campaign highlighted the similarities between leprosy and COVID-19, while the second campaign in autumn focused on Ajay from India, whose story was told through a short online video. Apart from building brand awareness in this campaign we also piloted ways to increase online donations.

The 2020 spring and autumn online communication campaigns resulted in great visibility among NLR's target audience, reaching 610,221 and 1,559,864 people respectively, which was more than expected. Both campaigns had a positive impact on traffic to our website and the number of followers of our social channels.



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

## Online visibility

In 2020 important steps were taken to further strengthen Leprastichting's online channels for communication and fundraising. We recruited an online marketer whose main task is to optimize our online presence. Throughout 2020 we increased the use of Facebook, Twitter and LinkedIn, resulting in an increasing number of followers. We also optimized our online newsletter and updated the website more frequently, which led to more visitors.

## Learnings in 2020

Social channels such as Facebook and Twitter have proven to be effective channels to reach target audiences and create brand awareness. In 2021 we plan to expand and optimise these and other channels in order to raise brand awareness and create fundraising opportunities. We will also pilot different approaches to see what works best. In addition, (free) media coverage, through press releases is essential to achieve a higher top-of-mind awareness with our target audience.





### International Brand Awareness

NLR is regarded as a valuable and trustworthy brand by funders, governments and implementing partners within the field of leprosy. Our core brand values should be well known and appreciated inside and outside NLR. We believe that a strong NLR brand is a driver in our ultimate goal of achieving a leprosy-free world. Perceptions of our technical capacity, leading role and innovative solutions are important assets that differentiate us from other NGOs. To maintain and grow a strong brand requires long-term investments, proactive and distinctive communications and continuous brand management.

### Focus and results

In 2020 we began focusing on four pillars: (1) recognizable branding across countries, projects and communication channels, (2) professional communication support to staff, platforms and projects, (3) increasing visibility of our work among target audiences, and (4) stronger internal branding.

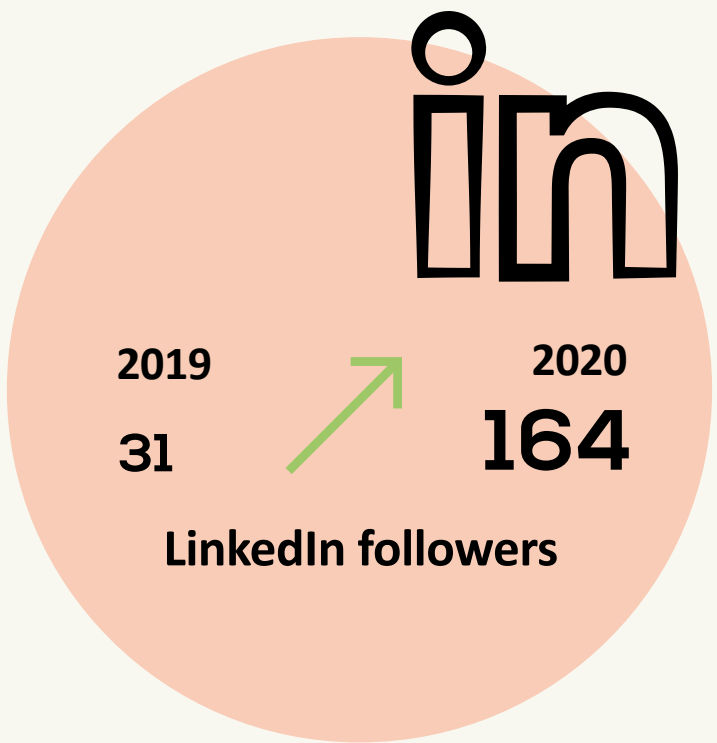
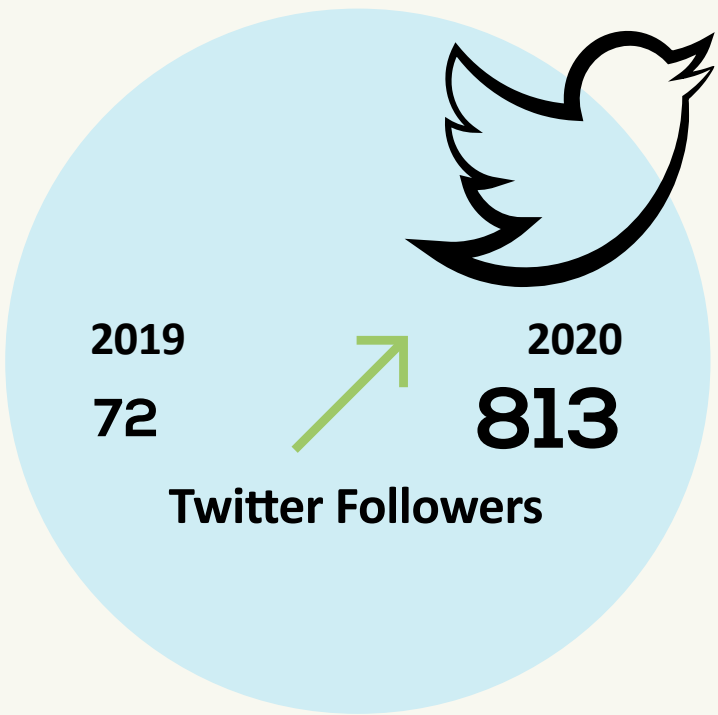
In 2020 NLR’s website was restructured to emphasize the Three Zero strategy and align external communication with this strategy. During the official launch meetings of the ‘Stop the transmission of leprosy project’ we ensured NLR was highly visible. A press release was issued for the launch in India resulting in more than 130 international media placements. As a global forerunner and advocate for SDR-PEP we developed an animated video that was launched

at the ISNTD (International Society for Neglected Tropical Diseases) Festival 2020. This video was very well received and is available with subtitles in Hindi, Bengali, Portuguese and English. A French version will be developed in 2021. We also renewed the layout of our Annual Report, the website of the Leprosy Research Initiative and increased focus on our social channels, resulting in more website visitors and followers.

### Learnings

We are still experimenting with the most effective ways to raise awareness through our international communication channels. However, we are already proud of our achievements so far and we regularly consider how we can improve our efforts. Cross-fertilization between offices turned out to be very important for gaining inspiration and exchanging knowledge. For instance, good photography is an important aspect of the communication strategy, but we experienced inconsistencies and differing content quality. To improve our photography and storytelling a three-day training session for NLR Alliance communication officers and LTR Nigeria was organised. As of 2021 we will start to implement the lessons learned and develop a content strategy.

## NLR: online channels in 2020





# COVID-19



## The impact of COVID-19 on NLR's work



# Challenges and Changes

## Impact of COVID-19 on our work

COVID-19 has impacted lives across the globe.

Depending on the national situation, governments in all countries where we work took measures with differing proportions to stop the spread of the virus. Early in the COVID-19 pandemic, countries across the world went into lockdown, shutting down or reducing national and international travel. This affected the interaction between countries for planning, monitoring, supervision, evaluation and learning purposes.

Clearly, the COVID-19 pandemic also affected our organisation as a whole and the implementation of the NLR-supported programmes in 2020. As of March, most fieldwork, project visits, meetings, trainings, travel, (face-to-face) conferences and other activities requiring people to interact while maintaining distance had to be put on hold.

Nevertheless, a lot has been achieved thanks to online alternatives and the creativity and commitment of NLR staff. We have all become proficient in organising online and hybrid events: meetings, trainings, discussions and face-to-face events respecting physical distancing.

## Emergency response actions

The NLR Alliance members adapted quickly and showed flexibility and commitment in supporting persons affected by leprosy, by organising emergency COVID-19 support. Right from the start of the pandemic, they made sure that persons affected by leprosy were included in COVID-19 response activities organised by the national authorities. NLR Alliance members also engaged in additional relief aid where needed, providing information, food and medicines, livelihood and personal protection and medical equipment. NHR Brazil conducted contact screening to help control the COVID-19 spread. Lessons learned on how to provide support through coordinated actions in line with the needs were actively shared within the organisation and with national and

international partners. In the second half of the year planned activities gradually resumed, taking physical distancing, personal protection and hygiene measures into account. Creating an enabling environment for the continuation of accessible leprosy health services remains a priority for NLR.

## Global challenges due to COVID-19

The pandemic affected the manufacturing and distribution of medicines, leading to constraints in the global medicines supply chain. This had consequences for the availability of the multidrug treatment (MDT) for leprosy as well as for the single dose rifampicin for the prevention of leprosy. MDT is essential for treatment of leprosy. If patients do not receive their treatment in time they are at great risk of developing irreversible disabilities. At the end of 2020 there was insufficient stock in several countries, leading to delays in treatment. Fortunately, this was resolved in early 2021, thanks to strong lobbying by the main stakeholders which led to a review of the supply chain, short-term solutions and long-term improvements.







### Expected impact for people affected by leprosy

It is too early to fully analyse the implications of the pandemic. However, some challenges with physical, economic, social and mental consequences are already clear: lockdowns and physical distancing constrain accessibility to services and therefore limit the availability of timely diagnosis and treatment and other key leprosy services, including prevention of disabilities, rehabilitation and mental healthcare. In some areas, the number of newly diagnosed patients has reduced by up to 70% compared to 2019. Late diagnosis and treatment lead to continued transmission and an increase in the number of people living with disabilities due to leprosy. Consequently, the number of contacts screened and receiving preventive SDR-PEP also reduced by as much as 90% and stopped completely during lockdowns in some areas. Most persons affected by leprosy belong to lower socioeconomic groups and are exposed to a greater risk of being infected with COVID-19 due to overcrowding and poor living conditions. Under these circumstances physical distancing and hygiene measures to prevent the spread of COVID-19 infection are difficult if not impossible to adhere to.

COVID-19 patients put under quarantine are at risk of discrimination and social stigma out of fear for spreading the disease. This stigma is often experienced by persons affected by leprosy, despite the fact that contact with a leprosy patient is much less likely to lead to disease. Persons affected by leprosy who contract COVID-19 experience a double burden: they may also be apprehensive to come forward for evaluation or testing for fear of quarantine and loss of income.

This confirms that there is a need for addressing the underlying social structures that translate into food insecurity, housing insecurity, lack of education, poor sanitary conditions, malnutrition or poor nutritional diets, and lives that lack dignity and equal opportunities.

### Positive outcomes

Whenever possible, face-to-face events were replaced by online alternatives including social media platforms and WhatsApp group discussions, or organised in smaller groups or in large spaces to facilitate physical distancing. We learned to appreciate the benefits of online alternatives for international meetings and conferences, such as reduced travel time, costs and climate impact and increased accessibility: a wider group could participate online compared to face-to-face meetings.

Some NLR Alliance members collaborated with new partners, especially at community level, to reach more stakeholders and more persons affected by leprosy and disability. Coordination with local Disabled Peoples Organisations ensured supplies such as MDT arrived in hard-to-reach areas. This kind of unexpected collaboration flourished in a few cases.

Several of these lessons can be integrated into our way of working when the COVID-19 pandemic is under control. We can continue support to persons affected by leprosy through mobile phones, SMS, WhatsApp, local radio, social media, etc. By organising online and hybrid events we will be able to use our time and resources even more efficiently.

Challenges related to the supply of medication have led to an evaluation of the distribution system. Improvements will lead to a more robust, resilient system in which supply chain weaknesses can be prevented and risks can be mitigated with more flexibility.





# COVID-19 emergency response stories

## Brazil

Rebeca Duarte is an occupational therapist at a health unit in Cabo de Santo Agostinho. Here she met Marcos André who lived with his wife Rivania for many years, but refused to take off his shirt in front of her. However, 11 years ago Marcos needed to do just that when he was bitten by a bug. Rivania noticed his chest was covered with marks and knew that he had some sort of skin disease. *“He said he was afraid that I would leave him”*, Rivania says.

After going to several doctors Marcos was finally diagnosed with leprosy in 2020 during the COVID-19 pandemic. *“He came in with many lesions, wounds on one foot, and bone resorption. He was also in a depressive and irritated state”*, says Rebeca, who made sure Marcos received proper treatment. Rebeca also coordinates a self-care group supported

by NHR Brazil at this unit.

During the pandemic she helped to distribute food and self-care items to patients in vulnerable situations. As she was talking to Rivania and Marcos at their first meeting, Rebeca found out that they had not eaten anything that day. As she learned more about their situation she decided to include them in the list of emergency response beneficiaries.

*“I receive 14 euros a month from the government. Our neighbours are all in a critical situation and I am ashamed to ask them for help”*, says Rivania. Marcos is still trying to get sickness aid and to get his disability retirement approved by the government. *“I cried when Rebeca appeared at our house with food. The night before, we only had coffee and rice”*, says Rivania.

With phone calls or visits Rebeca provides them with guidance about self-care measures. Marcos' foot no longer has open wounds, but because of leprosy disabilities of his hands and feet he still depends on his wife to perform daily activities such as eating, taking a shower, or putting on a face mask.





# COVID-19 emergency response stories

## Nepal

*"My name is Labhi Shakya and I work for NLR Nepal as a leprosy control programme coordinator. This year we had a tremendous amount of work planned in SDR-PEP administration to cover two entire provinces in Nepal. We were looking forward to working on our targets with great enthusiasm. Together with other coordinators, I visited municipal offices, the local government and provincial government to plan for the implementation of the SDR-PEP programme.*

*But when the pandemic hit we were clueless for some time. We didn't know where to start and how we could be of any help to our partners and local government of the areas where we have been working for years now. Since other coordinators were stuck in their own respective hometowns, I was responsible for looking after the emergency relief preparation and distribution.*

*With guidance from our supervisors, I conducted phone conversations with local people in each municipality within our working area. They had great expectations from our organisation and were in need of emergency relief materials and COVID-19 preventive materials.*

*We decided to support the municipality with some preventive materials and some medical equipment at hospitals to facilitate the treatment of COVID-19. We were unsure whether the materials we had supplied were actually reaching our target population, that is, persons affected by leprosy, persons with disabilities, children and pregnant women. We carried out lobbying and advocacy activities to ensure the vulnerable population of the community were provided with relief materials from the local government.*

*Major challenges in the process included not being able to be physically present in distributing many of the materials as the government has strict regulation on movement. But in the end we could collectively support the local government to control community transmission of COVID-19 and make sure persons affected by leprosy also benefited from our emergency response actions."*





# Three Zeros Strategy

## Introduction to Three Zeros

To work towards Zero Leprosy, the NLR Alliance has three strategic programmes: Zero Transmission, Zero Disability and Zero Exclusion. Together they contribute to our vision of a world without leprosy and its consequences.

Our Zero Transmission programme aims to break the chain of transmission of the leprosy bacteria.

Our Zero Disability programme aims to prevent persons affected by leprosy from developing new disabilities during or after treatment.

Our Zero Exclusion programme aims to improve lives for people with disabilities due to leprosy by supporting access to services and participation in community activities.

## Stigma

In all aspects of their lives, persons affected by leprosy are confronted with discrimination and stigma which fuels a vicious circle of negative consequences: social exclusion, lower levels of mental wellbeing and decreased economic independence. We therefore focus on reducing stigma and discrimination in each of our Zero-programmes.



# Zero Transmission



Over the past 20 years, NLR has invested a great deal in new approaches, the most prominent being the introduction of preventive treatment called post-exposure prophylaxis (PEP). The antibiotic that is proven to be effective as PEP for leprosy is a single dose of rifampicin (SDR-PEP). Combined with other approaches such as improved early case detection, development of diagnostic tests and vaccines, the use of rifampicin should make it possible to break the chain of transmission within the next few decades.

The objectives of the programme are:

- To improve early detection of leprosy, thereby reducing the percentage of newly detected leprosy patients with visible disabilities.
- To integrate preventive treatment into leprosy control programmes.

## Our Focus

A single dose of rifampicin (SDR-PEP) reduces the risk of developing leprosy by 60% when administered to contacts of leprosy patients. Continuation and scale-up of SDR-PEP as preventive medication for leprosy is one of our main objectives and is high on the agenda of the national programmes. However, the focus on the COVID-19 pandemic has challenged progress in 2020. NLR provided input for the WHO Technical Guidance paper, 'Leprosy/Hansen disease: Contact tracing and post-exposure prophylaxis', published in 2020. This is an important achievement in NLR's drive to support and facilitate countries to start implementing SDR-PEP.

## What we do

Strong lobbying and advocacy around the implementation and scale-up of SDR-PEP is an important component of the National programmes and our international networking. NLR also provides technical medical guidance. Over the last 10 years NLR has been involved in research and pilot projects related to SDR-PEP implementation. In collaboration with partners NLR has gained extensive experience and has developed training packs and implementation tools to provide programme managers with the support they need to integrate SDR-PEP administration into their routine leprosy control programme.



# Zero Transmission

## Flagship projects

### Stop the Transmission of Leprosy!

Financed by the Dutch Postcode Lottery's Dream Fund, the 'Stop the transmission of leprosy!' project seeks to interrupt the transmission of leprosy in two districts in each of the three countries with the highest global leprosy burden: Brazil, India, and Indonesia. As with most of NLR's fieldwork, the project was severely impacted by the COVID-19 pandemic in 2020 by delaying the clinical trial of the new preventive treatment. Over the last few years the study team has already encountered several obstacles that are often part of such a challenging intervention, so the team has become adept at finding ways to make progress regardless of the difficulties. Some highlights of the project under this year's challenging circumstances include:

- A milestone launch of the project in Brazil (March) and India (October) with high-level officials, groups of persons affected by leprosy and extensive media coverage. The nine individuals who took the ceremonial first doses were followed up and completed the full course of the enhanced treatment. The study launch in Indonesia was delayed due to the pandemic as many preparatory steps could not be completed in person.
- Following the first wave of the pandemic, the Brazilian team conducted a time-motion study to test all protocols and procedures. All project interventions were carried out by research assistants, recorded in the project database and timed by nurse supervisors. They approached 591

contacts of leprosy patients, received consent, examined them for signs and symptoms of leprosy and provided treatment to 158.

- The Community Education and Behaviour Change (CEBC) interventions were further developed and tested in all three countries. The team in India evaluated the impact of the interventions that began in October 2019 in a second perception study. Across the two districts, a total of 24,454 posters were displayed and 12,933 people were reached through stakeholder meetings. We found that our knowledge and awareness raising activities around leprosy and reducing stigma towards persons affected by leprosy in the communities had a very positive impact.
- In 2018 and 2019 we developed maps that show the areas of highest transmission based on GPS coordinates of new cases. These 'cluster' maps were updated with data from 2020 and will provide insight into the areas where we need to focus special attention due to higher risk. Within these clusters as many people as possible will be treated as part of intensified 'blanket campaigns' (coverage of complete communities) in the years to come.
- A series of key preparatory steps for the full randomised controlled trial were conducted, largely online. This includes the training of all research assistants and thousands of community health workers. In addition, the project database platform was developed collectively across all the study countries and tested in the field.





# Zero Transmission

## Flagship projects

### PEP4LEP\*

It is important to investigate which implementation methods are best for SDR-PEP in different contexts. PEP4LEP is a research project which compares the effectiveness and feasibility of two different SDR-PEP implementation methodologies in Mozambique, Ethiopia and Tanzania: a skin camp intervention and a health centre-based intervention. Skin camps are one-day community events in which skin screening and SDR-PEP administration takes place. They target around 100 community contacts of a leprosy patient. Participants in the PEP4LEP study are screened for leprosy and also receive screening and treatment for other skin diseases. In addition, NLR's SkinApp is used in this project as a tool to support community health workers to diagnose and treat skin diseases. In the PEP4LEP project approximately 30,000 contacts of leprosy patients are invited to receive skin screening and SDR-PEP when eligible.

In 2020 the project faced many challenges because of COVID-19, which limited field activities and caused delays in the import of rifampicin. Despite this major burden, we were able to achieve the following results:

- Trained over 100 local health staff members and leprosy researchers in Ethiopia, Mozambique and Tanzania.
- Successfully held international project meetings virtually.
- Collected baseline data in all three countries to describe the conditions before the project starts for later comparison to the data collected during and after the study.
- Set up the first skin camp for a leprosy endemic community in Tanzania.
- Administered skin screening to a total of 1,450 contacts of leprosy patients and SDR-PEP to 1,313 people in Tanzania.
- Received the Game Award of the ISNTD Festival 2020 for the NTD Skin Games "in recognition of the strong commitment to increasing education and awareness of skin conditions among healthcare workers". These two card games were developed to support health workers' training sessions.



EDCTP



\* This project is part of the EDCTP2 programme supported by the European Union (grant number RIA2017NIM-1839-PEP4LEP); it also received funding from the Leprosy Research Initiative (LRI; [www.leprosyresearch.org](http://www.leprosyresearch.org), grant number 707.19.58).





# Zero Transmission



## From the field

“The majority of leprosy patients is actually still in the communities”

Domingos Dreva

## Domingos Dreva's passion for leprosy work

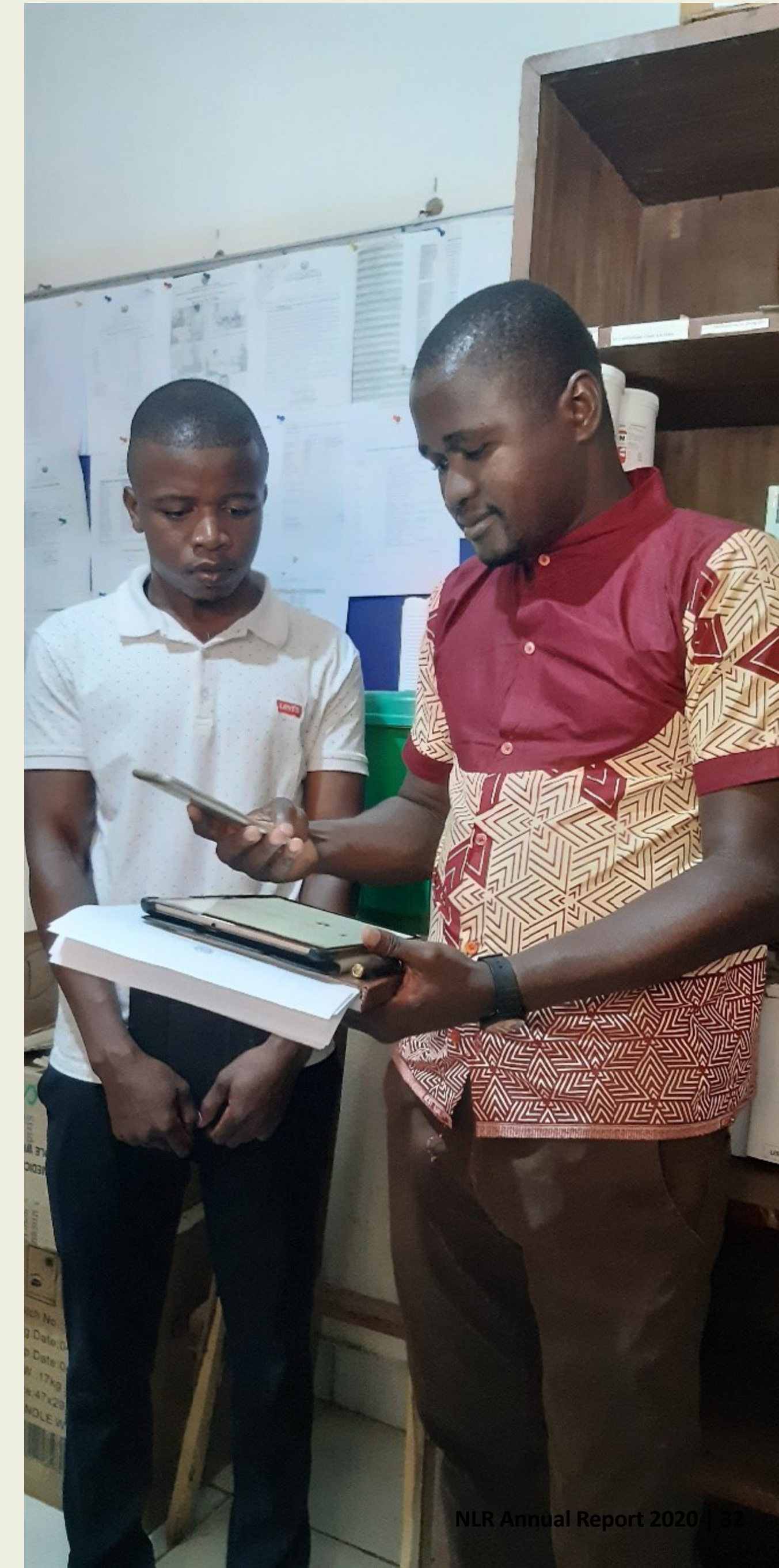
PEP4LEP – Mozambique (Provincial director for leprosy – government official)

*“After I graduated from nursing school, I worked as a general nurse in a health post. However, the nurse who specialised in tuberculosis and leprosy kept falling ill and needed to be replaced, but none of the replacements could stay very long. And although I was not officially trained in leprosy work, I had already substituted this nurse on several occasions, so I continued giving the tuberculosis and leprosy patients their medication.*

*To be honest, the patients at the health posts were a minority because the majority of patients remained in the communities. I started to go into the communities on a motor bike that was offered to me, and I saw for myself that the affected people are not just those that have been admitted to hospital. The majority of leprosy patients is actually still in the communities. We found patients who could not walk because of their ulcers and who were not able to go to a hospital.*

*So, when I went into the communities to do small campaigns, I encountered persons affected by leprosy. Some of them had lost all hope of a cure, and out of nowhere, I appeared with medication and a complete treatment.*

*I remember one time I encountered a woman who was affected by leprosy and could not go to a health post. I treated her, and when she was cured, she came to the hospital to find me and tell me that she was better, and thanked me. This really moved me. She did not have any more wounds, the ulcers had dried and closed and she was healed. That is when my passion for the leprosy work started.”*





# Zero Transmission

## Flagship projects

### Ready4PEP

Years of research and active lobbying by NLR have resulted in the adoption of SDR-PEP in the WHO guidelines. To apply this new knowledge in regular leprosy control, we started a three-year project in Mozambique and Nigeria in 2020. The national leprosy programmes are supported to introduce contact tracing and SDR-PEP, use new approaches like the SkinApp for active case finding, apply geographical mapping of cases, and strengthen overall capacity of health workers. Persons affected by leprosy are supported through self-care groups. This is done in collaboration with other ILEP partners active in the countries (The Leprosy Mission in Mozambique and Nigeria, and the German Leprosy Relief Association in Mozambique), each working in their own geographical areas.

In both countries, kick-off workshops were held that highlighted the commitment of all stakeholders, including organisations of affected persons. COVID-19 had a big impact on the purchase of rifampicin for the project, causing months of delay for actual distribution within the project areas. We hope to have this essential drug available in the countries at the beginning of 2021.

Although COVID-19 hampered our activities in the field, great progress was made this year:

- New methods and procedures to include SDR-PEP in the national leprosy control programmes were designed in technical meetings with ILEP partners and the Ministries of Health. These so-called PEP guidelines describe future standard operating procedures and new training materials.
- Organised COVID-19-proof Training of Trainers-sessions for leprosy staff from different regions in both countries. NLR International Office provided technical support from the Netherlands via an online connection. The interactive aspects of the training, such as role plays, the NTD Skin Games and the SkinApp, were received enthusiastically by the participants. Specific attention was paid to the topics of stigma and mental wellbeing.
- We trained country teams to improve their monitoring skills and to use of methods for the geographical mapping of leprosy cases in high endemic regions.





# Zero Transmission



## From the field

“Before, we thought leprosy was a distant reality. Now we are more aware of it”

Ana Cláudia Sá

## Story from Brazil

Ana Cláudia Sá is a community health worker in Vila Peri, a neighbourhood in the outskirts of Fortaleza where the first field activities for the **‘Stop the transmission of leprosy’** research project started in Brazil. Ana has been working in this area for the last 10 years and her daily activities include home visits to form a link between the families and the primary health care unit. She was trained by NHR Brazil and involved in activities to map leprosy patients, which was a real eye-opener for her: *“Before, we thought leprosy was a distant reality. Now we are more aware of it”*, says Ana Cláudia. People from the community contacted her to confirm details about the research: *“We have to fight disinformation. People trust this work when they see that it has a link with health units and community agents.”*

Ana Cláudia’s work on this project became even more personal when her mother-in-law was diagnosed with leprosy. Her family was evaluated as close contacts. Being more vigilant of the signs and symptoms, she took her son to the health service after noticing a patch on his skin in 2020.

Home visits by NHR Brazil’s research assistants involved in the ‘Stop the transmission of leprosy’ project also helped to identify 37 suspected cases in Fortaleza and Sobral. For example, Maria Ivanilda Tomaz was approached as a contact and the research assistants referred her to the health unit after identifying signs on her arm. She was diagnosed with leprosy. Her husband, José da Silva, who was diagnosed in 2017 says: *“I was treated and cured, and I believe the same will happen to her”*.

Aymée Medeiros, project coordinator in Brazil, is very proud of the project team and their results: *“Our presence in the field, even in the pandemic, indicates that the health managers are prioritizing leprosy, recognizing its epidemiological importance and recognizing our project’s role to fight and stop the spread of the disease.”*





# Zero Transmission



## From the field

“Everybody was so optimistic, and this spirit inspired me a lot”

Euis Sukaesih

## Story from Indonesia

In one of the endemic areas in West Java Province, Indonesia, a total of 800 leprosy patients have been registered in 49 community health centres from 2017 to 2020. In partnership with the local authorities and community health centres, NLR Indonesia implemented preventive treatment to break the chain of transmission and at the same time reduce stigma in the communities.

Stigma contributes to transmission because people affected by leprosy feel ashamed of going to community health centres. Moreover, leprosy patients prefer to visit health centres located further away from their home to prevent neighbours from knowing about their condition.

In the last quarter of 2020, a total of 6,973 contacts from 358 leprosy patients received preventive treatment (SDR-PEP) through home visits. Information on leprosy was vital to make people aware of early signs of leprosy and early detection.

One case showed how young dermatologists failed to detect leprosy in a woman, which caused disabilities. The woman saw several dermatologists to examine patches on her face, but she never received the right diagnosis. Luckily, she visited a local health centre for another reason. A health worker recognised the patches on her face and referred her to the leprosy health workers where she was then diagnosed with leprosy.

Even though most people we treat preventively are not sick or have no signs of leprosy, the project is really rewarding: *“It is a tough activity during a pandemic, but I felt so touched to see the people come and welcome us in this preventive treatment activity. Everybody was so optimistic, and this spirit inspired me a lot. We even diagnosed a child with leprosy who was a grandson of a former leprosy patient,”* says Euis Sukaesih (38), a leprosy health worker.





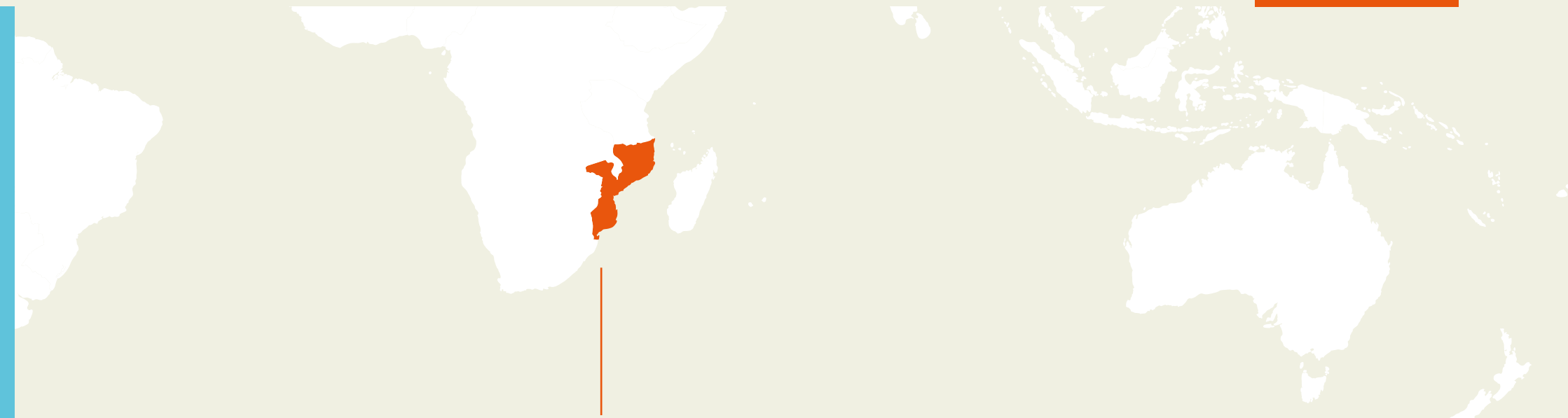
# Zero Transmission



## From the field

“I believe that many people in my situation are also happy to have been diagnosed early before any disability appears”

Nelda Gaspar



## Story from Mozambique

Nelda Gaspar is 11 years old and lives in Zambézia in the Mulevala District. She is in grade four in a local primary school:

*“My father saw my spot and had no doubt it was leprosy, because he had already had similar spots and was diagnosed with leprosy months ago. I felt bad about his discovery, even though I wasn’t diagnosed then. So, he took me to the community volunteer who referred us to the health technician. After all the tests, he said that I had leprosy and immediately gave me medicine and explained how to take it.*

*My spots are rapidly disappearing. I thank NLR and the government for always being with us and making sure that they come to the community to visit us and to give us the medications here in the community. I believe that many other people in my situation are also happy to have been diagnosed early before any disability appears”*







# Zero Disability



In our Zero Disability programme we develop interventions and aim to get public health services and government health policies to focus on two aspects of leprosy:

- Disability prevention: we pilot approaches, train health workers and lobby authorities for better services to prevent disabilities. Persons affected by leprosy are at risk of developing new disabilities during or after treatment. Patients may also get painful reactions after being treated with multi-drug therapy. Lifelong monitoring is required to prevent disabilities and the worsening of existing disabilities.
- Mental wellbeing: we explore interventions that reduce the impact of leprosy on mental wellbeing. Many persons affected by leprosy experience depression, anxiety and/or suicidal thoughts at some point in their lives, even long after they have been cured of the disease. Promotion of mental wellbeing is an important element in the fight against the consequences of leprosy.

## Our Focus

NLR wants persons affected by leprosy to learn and practise self-care, report complications, and demand assistive devices or reconstructive surgery when they need it. Persons affected by leprosy should be treated with respect and without being stigmatised, so they can feel confident asking health workers or staff of primary health centres for support. To encourage persons affected by leprosy to do this, community health workers need to take up their role in monitoring wound care, disability prevention and leprosy reactions. Health workers can motivate patients to visit a primary health centre in case of complications, and to promote regular self-care. In turn, these health centres need to train both community health workers and persons affected by leprosy so that they can carry out these activities. With up-to-date knowledge, primary health centres will be able to address disability prevention and complications. We

support health centres in their efforts to apply combined approaches with other diseases in the prevention of disabilities, especially neglected tropical diseases such as lymphatic filariasis. The role of national governments is to adopt and promote effective policies for the prevention of disabilities and provide assistive devices through these centres. NLR takes a leading role in networks that propagate these policies.

In 2020 mental wellbeing has become a more prominent theme for NLR and we are exploring interventions that can support the mental wellbeing of persons affected by leprosy. In the end we aim to achieve zero stigma and discrimination experienced by those affected and their families. An important condition is that health staff treats persons affected equally and provides counselling when needed, and that identified people in self-care and self-help groups of those affected by leprosy are able to provide peer counselling.

## Our efforts in 2020

To achieve the above, we piloted new approaches for the prevention of disabilities and for the promotion of mental wellbeing, and we supported the government to scale-up these approaches when they have been successful. We strengthened the capacity of health workers in the prevention of disabilities through the training of trainers. We stimulated the development of approaches for psychological peer support and the integration of attention to psychological support in counselling by health workers. We lobbied national and local authorities to implement policies, manage data and to allocate funds for the prevention of disabilities as well as for the promotion of mental wellbeing. We supported the development of guidelines and tools, knowledge sharing and learning through national and international platforms so that organisations such as the WHO and ministries of health will adopt the practices that we and others have developed.



# Zero Disability

## Flagship Projects

### Self-care groups in Brazil and India

Lockdowns in Brazil and India resulting from the COVID-19 pandemic have severely hampered disability prevention activities such as self-care group gatherings and face-to-face trainings on self-care. However, the NLR teams adjusted well and strengthened their virtual communication. Self-care group members and coordinators were contacted by phone, e-mail, WhatsApp or video calls so that support could be continued.

NHR Brazil reached out to self-care group coordinators and health professionals and involved more than 270 health professionals and students in lectures and online debates on the theme of rehabilitation and self-care groups. With support from universities, 24 cards with educational information were produced, 21 videos and four podcasts with guidelines ranging from self-care to prevention of COVID-19 were recorded and broadcasted. NHR Brazil thus strengthened the existing self-care groups in 14 cities in the states of Ceará, Pernambuco and Rondônia. There was no reported worsening of conditions among self-care group members and there were no reports of leprosy reactions. Home visits to leprosy patients with greater social vulnerability were carried out by the group coordinators who provided patients with hygiene and self-care kits. This benefited 229 patients and 771 family members.

NLR India used a combined self-care approach to address prevention and management of disability due to leprosy and lymphatic filariasis. Teaching self-care to persons affected by these diseases enhances safe mobility and increases their ability to perform daily activities. Under the COVID-19 restrictions in India, the NLR India team was still able to form 27 new combined self-care groups, and train 3,129 persons affected with leprosy and lymphatic filariasis, as well as health staff. During lockdown periods, most self-care group members were reached through virtual platforms to educate them about self-care practices and any issues raised by them were addressed. If urgent physical support was required, government health staff were contacted for their assistance. Ulcers with persons affected by leprosy improved in 96% of the cases, and 14 people could be referred for reconstructive surgery.





# Zero Disability

## Flagship Projects

### Peer Counselling in Primary Health Centres - Indonesia

A pilot project for peer counselling in collaboration with primary health centres started at the end of 2020. The initial results are promising, paving the way for the continuation of this project.

In this first phase, 10 persons affected by leprosy were trained in peer counselling skills. The training covered materials on leprosy, stigma, discrimination, depression and anxiety, and important interpersonal skills such as counselling and communication. At the same time, to ensure the sustainability of peer counselling at primary health centres, 10 leprosy and mental health workers were also trained in stigma, depression and anxiety issues, and the use of a standardised assessment tool.

Discussions revealed that many leprosy patients showed signs of mental health problems such as depression, lack of acceptance and reactions to leprosy that might induce stress. The importance of mental health problems around leprosy and its relation to stigma was increasingly recognised. Health workers described how many leprosy patients remain unable to accept their condition and lose motivation to carry out activities, and now realise that these patients need not only medical but also psychological counselling. The presence of peer counsellors helps persons affected by leprosy to overcome this problem by sharing stories and experience and providing relevant suggestions.

We identified some interactive peer counselling training methods such as quizzes, games, audio-visuals and exercises that can facilitate learning by persons affected by leprosy. At the same time, the COVID-19 pandemic imposed social distancing rules, which prohibited normal interaction and in a few cases created some distress among participants.

A total of nine peer counsellors are now actively providing peer counselling sessions in five primary health centres. We expected that by the end of 2020 at least 50 persons affected by leprosy would complete six counselling sessions as clients. However, because of the pandemic related challenges, only 20 of them are currently undergoing counselling sessions.





# Zero Disability



From the field

Pratistha continues to show remarkable improvements in her ulcers and wounds caused by leprosy.

## Story from India

Pratistha Kumari is a 19 year old woman and a regular participant in the self-care camp. She struggled to ensure her livelihood and support her family and during the pandemic, she was unable to practice the self-care regime for her condition. Many persons affected by leprosy suffer the same fate – they have to choose between adhering to the restrictions imposed by COVID-19 or dealing with the underlying health conditions caused by leprosy.

NLR India staff came up with a digital solution to this growing problem: an innovative idea for virtual self-care training and monitoring. However, this solution came with a few hurdles of its own, particularly the lack of electronic devices like smartphones, laptops and desktop computers. NLR India staff motivated persons affected by leprosy to either join the session in groups or borrow these devices for the session from their relatives, friends and acquaintances.

In the first few sessions, the idea was to motivate and reach out to as many persons affected by leprosy as possible, and that included Pratistha. The staff counselled the participants to work towards their essential needs and support each other. After making the participants comfortable, the staff began the sessions for resuming the self-care practices to ensure their conditions did not get any worse. Pratistha Kumari was one of the direct beneficiaries who continued the self-care practices and followed the advice and instructions provided by staff. As a result, she continues to show remarkable improvements in her ulcers and wounds caused by leprosy.





# Zero Disability

 From the field

“I learned how to take care of my hands and feet”

Tomás

## Story from Mozambique

Tomás Manteiga Mussa (33), father of four (a son and three daughters), was diagnosed with leprosy during an active case-finding session carried out on the day of a trade fair in his community. He started treatment on the same day and then was referred to the self-care group.



*"I learned how to take care of my hands and feet to avoid wounds and disabilities. I've been practicing the techniques and am constantly trying to perfect them. I told myself that if I mastered the self-care practices, I could do it at home and prevent further disabilities. With the outbreak of COVID-19, there was a ban on group gatherings which made it difficult to learn everything. Sometimes, I requested support from the local volunteer to remind me of what was taught in the group and since then I have received a basin through NLR Mozambique and started practicing in my house."*

Floriana Mateus (23), Tomás's wife, confirms: *"In addition to treatment, he soaks his feet and hands for a while and then begins to brush them, as he learned in a self-care group. He explained that these practices prevent wounds from appearing. I can see he is improving. The disease is not causing him any further disabilities and he is still able to carry out daily activities on the farm and at home. Thank you very much."*





# Zero Disability



From the field

“I want to get better so I can be back with my family”

Eric

## Story from Indonesia

The look in his eyes was disheartening. A somber-looking man named Eric was examined by a senior technical advisor from NLR. We visited him at his relative's house in North Sulawesi. He was married and had a normal life before he began to experience several symptoms that turned out to be caused by leprosy. He was kicked out of the house and instantly lost what he cared about most in life: his family.

Persons affected by leprosy often experience stigma and discrimination due to lack of understanding and misconceptions about the disease. Eric's wife's family asked him to move out of the house because they were scared he might pass the disease on to other family members. *“I felt like my heart had been ripped out,”* he said as tears streamed down his face. He found it hard to seek treatment and he lost the will to stay healthy when his family left him.

The leprosy team found Eric just in time, correctly diagnosed him, and proceeded to assess his physical and mental wellbeing followed by gradually evaluating his condition to determine the kind of help that would be suitable for him. The team also helped him with his confidence and motivation. They keep in touch and constantly remind him that he is worthy of having a better life. After series of consultation and counselling, Eric finally said: *“I want to get better so I can be back with my family.”*





# Zero Exclusion



Persons affected by leprosy face major barriers for equal participation in society. It is not only the physical effects of leprosy that devastate the lives of those affected. Social stigma and discrimination contribute to difficulties for equal participation in communities and society in general. Prejudice and negative attitudes exclude them from social and economic activities. Persons affected by leprosy often experience feelings of low self-esteem and self-worth. Stigma can come from family, community members and, unfortunately even health workers and sometimes the law. In 2020 we focused on the following:

- Supporting, strengthening and training of self-help groups, associations and disabled people's organisations to improve their work for their members. In all countries we made use of approaches at community level to include persons affected, working towards disability-inclusive community models.
- Ensuring that persons affected by leprosy receive the correct information and support and are aware of their rights. Those affected are the best spokespeople to stand up for their own rights and serve as positive role models for their peers. We strengthen self-help groups and associations by enabling them to voice the concerns and needs of persons affected to authorities and service providers. The inclusion

of persons affected by leprosy in disabled peoples organisations can strengthen their voice, improve their inclusion in society and the realisation of their rights. International treaties ratified by many countries such as the UN Convention on the Rights of Persons with Disabilities and the UN Principles for the Elimination of Discrimination Against Persons affected by Leprosy and their Family Members, were used as entry points to lobby for an inclusive political agenda at national and international level. We joined forces with other ILEP organisations and the broader International Disability Movement to strengthen our (inter)national lobby.

In 2020 working on inclusion became more difficult because of the pandemic. Luckily, however, organisations of disabled people and those affected by leprosy that we work with were able to keep in touch with the communities during the lockdown periods. They kept us informed about the adverse effects of the pandemic on affected people in the communities. They helped identify shortages of drug supplies and in some cases even to get leprosy medication to remote villages where it was needed.



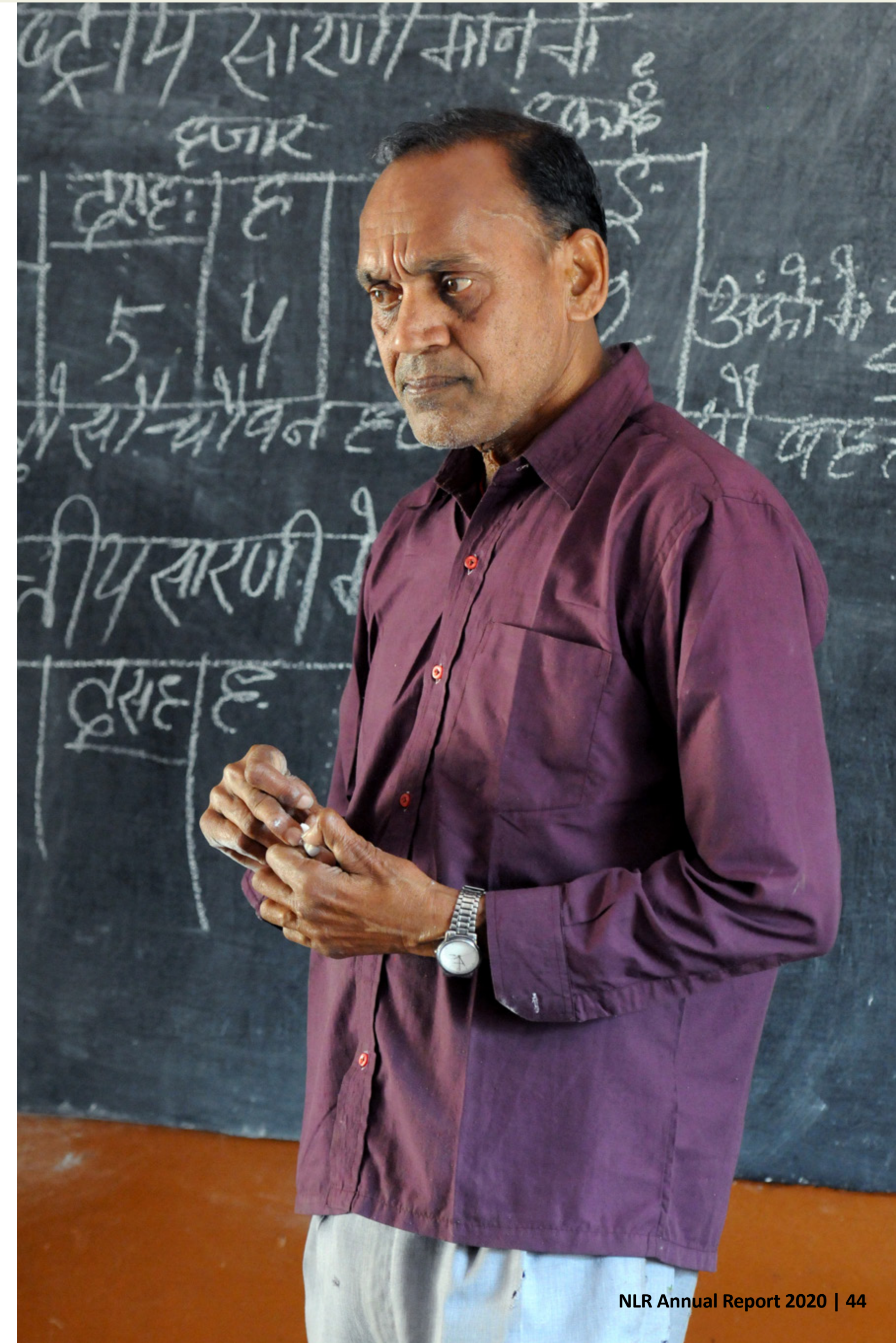
## Our efforts in 2020

At international level we worked closely with Alice Cruz, the UN Special Rapporteur for elimination of discrimination against persons affected by leprosy. Her mandate was extended in 2020 with the help of joint lobbying by NLR and other ILEP members. We also contributed to national recommendations on the United Nations Convention on the Rights of Persons with Disabilities (Indonesia) and the Convention on the Elimination of Discrimination against Women (CEDAW) with other ILEP members in Brazil.

Lobbying for social rights and greater inclusion for persons affected by leprosy is an important focus area. For instance, In the 15 municipalities where we work in Nepal, Health Insurance is now free for persons affected by leprosy and for those who have a disability. A series of lobbying activities by Indonesian disabled people's organisations prompted village governments to allocate funds for inclusive activities. NLR Indonesia contributed to an important national Ministerial Regulation prioritising Village funds, including the regulation of inclusive villages.

To improve the socio-economic situation of persons affected a variety of activities were set up in 2020. For example, in Mozambique 16 inclusive farmers' associations were registered. In Brazil, persons affected successfully started online sales of their bio-jewellery production, an innovative project that the Brazilian Ministry of Health would like to replicate. In India eight new self-help groups in Delhi now use a loan system for setting up small businesses. Strengthening capabilities of the target groups also generates champions and role models, such as the 180 change agents (community volunteers) identified in India in 2020.

We facilitated learning between different country programmes and successful methods are shared with other leprosy and disability organisations to promote upscaling of best practices.





# Zero Exclusion



## Flagship Projects

### Inclusion in Mozambique

Levels of exclusion in Mozambique are generally high, which makes it even harder to achieve inclusion of persons with leprosy and/or disabilities. Therefore, NLR Mozambique's approach relies on partnerships with larger advocacy groups to push for inclusive practices at community level. 2020 saw the conclusion of a two-year project in Zambézia province on inclusive health and agriculture. Community members in two districts were informed about the rights of people with disabilities and pressure groups were set up comprising members of inclusive self-help groups to address the needs of persons affected by leprosy and to claim their rights to participate in local social development. This has led to positive, concrete results. Those affected have been included in local planning forums and ramps for people with disabilities have been installed in some institutions, which beforehand would have been unthinkable. Many members became powerful voices in meetings and role models for their peers in the community.

A disabled people's organisation in Nampula province called ADEMO-Monapo was invited to take part in this project. It's members learned how to go about training and they created task forces and pressure groups. They saw how powerful people with a disability can become when they are organized. Testimonies shared by those affected by leprosy on reductions in stigma by community members and in schools were impressive. ADEMO-Monapo replicated these interventions, setting up and strengthening the capacity of eight local task forces in their own areas.

In 2020 these groups were able to participate in local decision-making processes and lobbied for the needs and rights of beneficiaries to be included in the public agenda. One direct result was the inclusion of 32 persons affected in social protection programmes. A local basic social allowance access point was established close to one of the self-care groups.





# Zero Exclusion



## Flagship Projects

### The LEAP project

The LEAP Project (in full: Local Economic Development of People with Disability through Active Advocacy for an Inclusive Policy) in Indonesia aims to improve inclusion in the economic sector, specifically through formal and informal employment. Training sessions were conducted to improve knowledge of disabled people's organisations, government agencies and other stakeholders on legal policy, the right to work and entrepreneurship of people with disabilities. Three local disabled people's organisations in Sulawesi were actively involved in setting up a comprehensive database to support local government in developing inclusive programmes. This will be used to increase the access to social services and government employment programmes for persons affected by leprosy.

Two pilot programmes were implemented to promote entrepreneurial opportunities and access, and inclusive jobs for people with disabilities and those affected by leprosy. A total of 34 people with disabilities (five of them affected by leprosy) were trained for formal jobs and 121 with a disability (14 of them affected by leprosy) strengthened their entrepreneurial skills. These two programmes serve

as a reference for government and the private sector, which currently lack knowledge of how to implement inclusive employment programmes. Another positive result of these pilots were signed agreements between four disabled people's organisations and governmental vocational training centres to provide inclusive services and wider access for people with disabilities and those affected by leprosy within the training programmes.

Disabled people's organisations strengthened their capacity to conduct evidence-based advocacy and awareness raising. Three of these organisations in South Sulawesi successfully developed policy briefs and legal drafts on the topic of employment for people with a disability. A legal draft on implementation of empowerment of workers with disabilities was enacted by the district government of North Toraja. Legal drafts are in final review by local governments in two other districts. Information from the database and the two pilot programmes were used as evidence. These policies will create opportunities for involvement and increase access to work for people with disabilities and those affected by leprosy.





# Zero Exclusion



## From the field

NLR India ensured educational support like school fees, school uniforms and stationary for Mithu and Masooma

## Story from India

In leprosy colonies throughout India children dream of quality education, but their dreams are never realized because of the multiple socio-economic hurdles experienced by persons affected by leprosy.

NLR India is helping children like Mithu Banerjee and Masooma Shah to follow their dreams. Both girls live in a leprosy colony in the state of West Bengal. Their fathers have leprosy and earn their living by begging on the street. With increasing economic constraints, Mithu and Masooma were on the verge of dropping out of school to support their families through child labour.

Working with the Netaji Leprosy Colony, NLR India staff identified the concerns and growing requirements of educational support for the colony's children: educational support like school fees, school uniforms and stationary to ensure Mithu and Masooma could continue receiving an education. Further discussion with their parents revealed that that tuition support is required for many children like Mithu and Masooma across the leprosy colony.

NLR India staff hired a local tutor, Mr. Dipak Ghosh, to provide classes to children of the leprosy colony. All the residents expressed their gratitude towards NLR India for their support for their children's education. An initiative that began with helping two children, Mithu and Masooma, resulted in helping many other children in the leprosy colony.





# Zero Exclusion



## From the field

“We got all four stakeholders together to share the problem among each other”

Himalaya Sigdel  
(Country Director NLR Nepal)

## Story from Nepal

This year, COVID-19 has made it was very difficult to conduct door-to-door programmes or mass meetings to discuss the needs of people with disabilities and those affected by leprosy.

When the national lockdown in Nepal started in the first quarter of 2020, NLR Nepal and the National Federation of the Disabled were at first uncertain what they could do for these communities. NLR Nepal then strengthened members of the disabled people's organisations along with the National Federation of the Disabled.

Both organisations lobbied with municipal authorities and convinced them to provide a meeting room for members to conduct their monthly meeting to share the issues faced by persons affected by leprosy and those with disabilities. NLR Nepal's Country Director Himalaya Sigdel is very proud and he said: "We got all four stakeholders together to share the problem among each other." The municipality even supplied the room with drinking water, a computer and a printer. It is now open during office hours to accommodate persons affected by leprosy and people with disabilities.

One of the members assists the visitors in printing their essential documents and drafting letters and he is financially compensated for his services. More importantly, these monthly meetings have helped to raise their issues and make their voices heard by the authorities. The municipalities now recognize the importance and needs of disabled people's organisations at local quarter and municipality level.





# Indicators

Multiple interventions are necessary to work towards a world free from leprosy. In the countries where we work (Brazil, India, Indonesia, Mozambique and Nepal) NLR supports active case finding of new leprosy patients and distribution of preventive treatment. We focus on proper training of health staff. Relevant and up-to-date knowledge and expertise of health workers is crucial in the public health system's fight against leprosy. It is therefore essential to train health workers – particularly training the trainers – about leprosy, the prevention of disabilities due to leprosy, and the reduction of stigmatising attitudes towards persons affected. Moreover, together with local actors we work towards full inclusion in society of persons affected by leprosy. These are the indicators of our impact.

“Thanks to the mentoring provided by NLR through groups, I have the confidence and ability to be involved in activities in the community.”

Firmansyah

## Zero Transmission



The number of new patients detected has been closely monitored over the years. This provides an indication of the extent to which the disease is still actively spreading. It also reflects the quality of the leprosy control programme: more active searching leads to an increase in the number of newly detected patients.

The incubation period (the period between infection and development of disease) for leprosy is 3-5 years on average. Looking at the number of children among newly detected leprosy patients is therefore an indication of recent transmission. It also indicates efficiency of detection and diagnosis.

NLR is very keen to support the implementation of SDR-PEP in endemic countries. This will speed up getting to zero leprosy. We closely monitor the number of areas where the intervention has been implemented and how many people have received the preventive medication.

Data are preliminary due to reporting delays in India caused by the COVID-19 pandemic

24,176

Newly detected leprosy patients in NLR intervention areas



1,529 children

Among those new leprosy patients



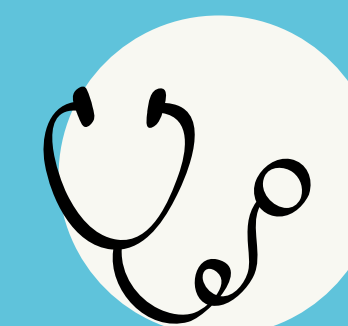
54,027

Contacts received SDR-PEP in 158 areas



4,384

Health staff trained on leprosy



## Zero Disability



NLR trains health staff so they can offer better services to prevent persons affected by leprosy from developing new disabilities during or after treatment.

1,936

Health staff trained on prevention of disabilities due to leprosy



## Zero Exclusion



- Voicing concerns: we strengthen self-help groups, associations and disabled people's organisations to enable them to voice the concerns and needs of persons affected to authorities and service providers. This encourages those affected to claim their rights and to be fully included in society.
- Improving socio-economic participation: equal participation in society is a basic human right. For example, being able to access loans, agricultural inputs, or (for leprosy affected children) being able to attend school, will enhance their socio-economic situation.

2,350

Health staff sensitised on stigma



2,487

Local actors better voicing concerns and needs of persons affected



2,284

Persons affected with improved socio-economic situation





# Highlights







# Launch 'Stop the transmission of leprosy' in Brazil and India

In 2020 NLR, NLR India and NHR Brazil officially launched the **'Stop the transmission of leprosy'** project in India and Brazil in the presence of key national stakeholders, media and contacts of persons affected by leprosy who received the first dose during the launch ceremony. With the project NLR aims to reach 800,000+ contacts of persons already diagnosed with leprosy in India, Indonesia and Brazil. The project is funded by the Dutch Postcode Lottery through its Dream Fund.

# Start of Ready4PEP project in Mozambique and Nigeria

With the Ready4PEP project NLR began to implement SDR-PEP, a preventive treatment to stop leprosy transmission, in Mozambique and Nigeria. NLR, NLR Mozambique, LTR Nigeria and a wide range of partners aim to interrupt the spread and devastating effects of leprosy through well thought-out interventions targeting a range of stakeholders. The approach to implement SDR-PEP considers four crucial elements: active case finding, geographical mapping, building the capacity of health workers and the distribution of medication.

Governments of both countries have shown enthusiasm and willingness to work together with the partners in this project to introduce SDR-PEP into their leprosy control programmes and improve care for those affected.







# Guides on Stigma and Mental Wellbeing

In June 2020 the International Federation of Anti-Leprosy Associations (ILEP) and the Neglected Tropical Diseases NGO Network (NNN) launched [a new website](#) to enhance understanding of stigma, what can be done to reduce it and to mitigate its impact. NLR staff played a key role in the development and promotion of the guides incorporated in the site.

The guides are designed to increase awareness and understanding and help to strengthen the technical and interpersonal skills required to handle stigma and its repercussions. The goal is to remove the taboo of speaking about mental health and to help end NTD-related stigma.

The Stigma Guides were promoted with a [video](#) at a WHO webinar and a COR-NTD conference. NLR produced the video that was shared by partners and through various channels.

# SDR-PEP animation release

We developed an animation about the importance of SDR-PEP which premiered at the ISNTD Festival in March 2020.

One audience member stated:

*"This film is amazing. The message is so clear: this is the problem, and this is the solution."*

[Click here to see for yourself!](#) (available with subtitles in Hindi, Bengali, Brazilian Portuguese, Bahasa and English).

The video is used for lobbying and advocacy to promote SDR-PEP implementation and it has been picked up internationally.

# Increasing donor support

It is only thanks to the ongoing support of loyal donors and valued partners that we are able to overcome challenges, engage in emergency response activities and continue our work.

At the Leprastichting, NLR's Netherlands' office, the individual donor base grew from 43,116 to 44,996 relations. This resulted in an increase in donations from 124,788 in 2019 to 136,112 in 2020. On behalf of everyone affected by leprosy, we thank you for your support in 2020!







# Leprosy e-learning modules for health workers in Indonesia

In collaboration with NLR Indonesia the Ministry of Health launched a digital training module for leprosy prevention and control. The modules are designed for health supervisors to acquire accurate diagnostic skills and provide adequate understanding and technical ability in the field. The intention is for governments to implement this module at national, provincial and local levels at a time when keeping distance is required during the COVID-19 pandemic.

# Propelling performance with Partnerships

NLR's mission to stop the transmission of leprosy can only be achieved in partnership with others, so cooperation is the basis of our work.

NLR and NLR Nepal teamed up with AIM Initiative/ALM to map people with leprosy in Nepal in order to make SDR-PEP implementation and new case detection initiatives more effective. A useful best practice will be developed with tools, protocols and flow charts. These will be made available to and used by global ministries of health and NGOs when implementing SDR-PEP. Additionally, tools for data management, data collection and data analysis will be shared to help others carry out mapping themselves.

In 2020 NLR and NHR Brazil have also initiated new collaborations. NHR Brazil is working with UNESCO to implement strategies to combat stigma among persons affected by leprosy and other neglected tropical diseases.





# Our Organisation







**Achieving Zero Leprosy requires a solid organisation that allows flexibility to make changes when necessary. We were able to focus on supporting persons affected by leprosy in the midst of the pandemic and worked to achieve our goals with integrity. This was only possible because of the hard work and dedication of our office and field staff, our Supervisory Board, donors, volunteers and our collaborating partners. We are very proud of their resilience, strength and perseverance. We worked from home and kept our distance, but together we achieved great results and kept our eyes on the goal of a leprosy-free world.**

# Staff Composition

NLR's International Office is based in Amsterdam, the Netherlands, where at the end of 2020 our staff comprised 39 employees (33.7 FTE) and 350 volunteers. In 2020 the management and implementation of field activities was delegated to five professional country offices located in Mozambique (18 employees), India (74 employees), Indonesia (56 employees), Nepal (21 employees) and Brazil (31 employees). Together, these country offices employ a total of 200 people, including 67 research assistants across the different locations.

## Sickness absence rate

The national average rate of overall absence in the Netherlands in 2020 was 4.4%. NLR's target maximum is set at 4.1%. However, the overall absence rate in 2020 was 11%, an increase compared to 6.2% in 2019. Seven employees had to deal with long-term sickness absence due to various reasons, which accounts for 91% of the total sickness absence. This high rate of long-term sickness absence is being monitored closely by HR and management and a plan of action is in place to counter this in 2021 and beyond.

## Working place and conditions

COVID-19 has shown us that the possibilities of working from home are much more extensive than we had assumed. We have made it possible for employees to borrow office furniture for an ergonomically sound working environment at home. We have also implemented an adapted travel and working from home expenses policy. After a new national lockdown in the Netherlands in December 2020, we offered employees the option of taking up to 50% paid leave to accommodate their challenging situations at home. Lastly, in 2020 we initiated a follow-up of the Risk Inventory and Evaluation (RI&E) which has informed plans for the future of our office layout, organisational culture and health services.

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





### Employee Representative Body

Employee participation is a great asset for NLR in several ways. Employees can influence decisions that are important to them, the CEO receives input on plans and insights from across the organisation.

The Employee Representative Body is entitled to advise NLR's CEO on planned changes in the organisation, labour conditions and terms of employment that affect more than 25% of staff at the International Office. In 2020 the body was involved in designing and planning the risk inventory and evaluation and gave its consent to a plan of action to address identified risks which affect staff. The high workload for staff is classed as top priority. In addition, the Employee Representative Body gave positive advice on a new scheme for the reimbursement of travel expenses and measures taken by the CEO due to COVID-19. After a period of two years in this role the members passed the baton on to their successors.

### Risk analysis and control

NLR Alliance members and the departments at the International Office conduct an annual risk analysis. This analysis identifies the main threats to the (continuity) of our operations. To mitigate these risks, controls are identified and put in place.

To control our operations we have systems in place to monitor both our financial progress as well as the progress of our in-country leprosy projects. This ensures that our spending is in line up with our strategy and accountability principles. In 2020 four quarterly financial reports were produced which were discussed by management as well as NLR's Supervisory Board.

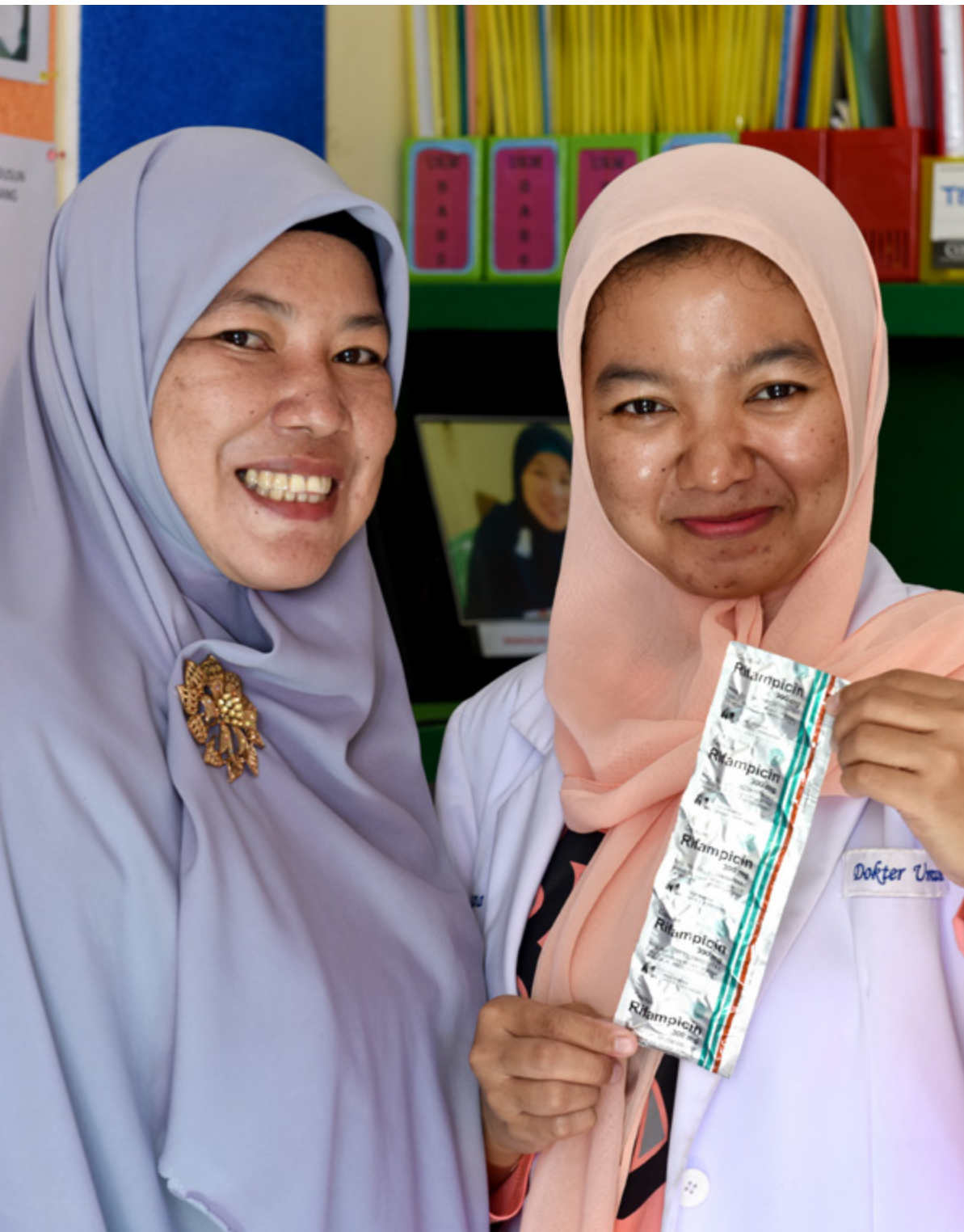
### In control statement

NLR has mapped out the risks it faces, assessed the likelihood of these risks occurring and their possible impact. Management measures are linked to these risks to ensure early warnings, minimize their occurrence and, where possible, their impact. The Supervisory Board expressed confidence that NLR has sufficient control over the risks identified.

### Quality system (ISO)

NLR received the ISO 9001:2015 and the branch-specific ISO 9001:2015 Partos certifications in November 2017. These certifications are valid for three years and, following a renewal audit by an independent auditor in 2020, they have been extended for another three years. The audit highlighted several improvements that could be made to our system. These will be addressed in 2021 and beyond.





### General Data Protection Regulation (GDPR)

Adhering to the General Data Protection Regulation is part of our day-to-day operations and a key attention point for our organisation. We have appointed a data protection and privacy officer who monitors any issues that may arise related to data protection.

Compliance and security measures already in place were continued and consolidated in 2020. We ensured that all our suppliers and vendors are operating in line with the GDPR. Agreements have been made with new cooperation partners on the exchange of data and associated security measures. No data breaches regarding the compliance with the General Data Protection Regulation were reported.

### IT and office investments

In 2019 we began an IT renewal programme focusing on NLR's hardware and software. Fortunately, this programme was well underway by the start of the COVID-19 pandemic, enabling staff to work comfortably from home from the outset. In 2020 we have followed up on these investments, embedding working in the cloud further into our organisation. In addition, two major IT projects were undertaken in 2020: the development of a new Customer Relationship Management system (CRM) and a Grant and Programme Management system. Both systems enable us to manage our work more efficiently and effectively. Further planned investment in our office layout has been postponed until mid-2021 because of the pandemic.

### Corporate Social Responsibility

NLR operates on a carbon-neutral basis. As in previous years, in 2020 our CO2 emissions from air travel and printing were compensated by contributions to sustainable energy projects. Naturally, our carbon emission was significantly reduced as staff worked mostly from home and air travel only took place in the first three months of 2020.

In accordance with the Financial Management of Fundraising Institutions guidelines issued by Goede Doelen Nederland (Dutch charities branch organisation), our key goal in the management of our reserves and funds is the preservation of our capital. In line with our investment policy, we invest exclusively in financial products offered by governments and companies that respect human rights, reject child labour and manage their operations sustainably.





# Integrity

In our work we focus on a vulnerable group of people who must be treated with respect and dignity. Our donors entrust us to spend our financial resources responsibly and expect our staff and partners to act with integrity. In 2020 we drafted minimum quality standards for the integrity policy framework for all NLR Alliance members. These standards cover:

- The overall integrity policy
- The Code of Conduct
- The Complaint & Whistle-blower Policy
- The Anti-Fraud & Anti-Corruption Policy
- The Policy on Inappropriate Behaviour
- The Communication Policy & Crisis Protocol

This has already been implemented at NLR's International Office in previous years and is now being updated by NLR Alliance members. In addition, NLR Alliance members agreed the following:

- To install a local integrity officer and a local confidential advisor
- To conduct an annual risk assessment on integrity
- To inform all staff about the integrity policy framework and bring the code of conduct to the attention of all staff annually

As a result of these agreements, four of the five Alliance members have appointed an integrity officer for their office and two members have appointed an external confidential advisor. Four country offices decided to update their policies based on the new standards, while the fifth has already updated all its policies.

As in previous years, all staff once again reviewed our Code of Conduct and related policies during an online meeting. In preparation for this meeting staff were asked to complete a questionnaire comprising of statements about integrity and the results were discussed during the meeting which was organised and moderated by the integrity officer. The confidential advisor also attended the meeting and introduced herself once again, so that all new staff had the chance to get to know her and her availability when needed.

## Issues report

Two integrity issues were reported to our Alliance members in 2020. The complaints related to the management style and were investigated by the integrity officer via interviews with those who submitted the complaints. Following the results of the investigation the Alliance members in question assessed the well-being of staff and the management style they experienced by circulating an anonymous questionnaire, the results of which have led to further actions for improvement. The confidentiality advisor did not receive any complaints in 2020.

In the office of one of our international project partners, irregularities in the financial administration were detected through routine internal procedures. The partner organisation immediately notified NLR about these irregularities and discontinued project activities. The staff involved were dismissed and an external auditor was contracted to investigate further. As coordinator of the project concerned, NLR notified the project donor and the other project partners. The project partner organisation is evaluating the situation and will refund the budget involved as well as implement organisational changes.



# Governance

## Supervisory Board

The Supervisory Board is the NLR's highest governing body. It oversees the performance of our CEO as well as our policies and the general course of affairs. The CEO is responsible for the organisation's management and in executing his/her role, he/she is supervised by the Supervisory Board.

In the bylaws the division of responsibilities between Board and management is specified in detail. Supervisory Board members serve a maximum of two terms of four years each. The Supervisory Board meets the criteria of the Dutch Management and Supervision Act (Wet Bestuur en Toezicht) which, among other things, requires gender diversity. The NLR Board comprised of two female members and four male members.

In 2020 the Supervisory Board comprised the following members:

### Mr A. van Ojik

#### Chair

Second term, until 1 January 2024.

- Member of the Dutch House of Representatives on behalf of Groen Links (the Green Party).

### Mr P. R. Klatser

Second term, until 15 March 2021.

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

### Mr R. L. J. Greveling

#### Chair, Financial Audit Committee

Second term, until 31 December 2021.

- Partner KPMG Accountants N.V.

### Mrs E. J. C. Bongers

Second term, until 19 May 2025.

- Executive Board, Beweging 3.0 as of 1 December 2020.
- Vice-Chair, Supervisory Board of Dianet.
- Member of the Supervisory Board, Viattence.

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

Second term, until 1 April 2023.

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

### Mr M. R. A. van Cleeff

#### Chair, Technical Committee

Second term, until 1 June 2023.

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



# Main activities and decisions of the Supervisory Board

Unfortunately, due to COVID-19 the annual visit to the International Office and meetings with NLR’s staff were cancelled. For the same reason Supervisory Board members were unable to visit a leprosy programme in the field in 2020.

The Financial Audit Committee met four times to discuss a variety of finance-related issues in preparation for the board meetings. In addition to regular financial products like annual budgets, quarterly reporting and annual accounts; updates on our investment portfolio, IT programme and the NLR transition track were discussed by the Financial Audit Committee.

The new Technical Commission met twice to monitor and discuss the efficiency and impact of NLR’s expenditure on programmes and technical projects and to advise the Board.

In 2020 the Supervisory Board addressed the following:

- Progress Reports presented by the CEO on the execution of the annual plan and budget were discussed on a quarterly basis. The measures and consequences of COVID-19 for the International Office as well as the Alliance members, the staff and field work, were also discussed in every meeting. In its September strategy session the Board was further informed about the challenges due to COVID-19 and discussed in-depth its current impact on programmes, fundraising and the organisation, as well as potential consequences in the near or longer-term future.
- The transition process of NLR from an organization headquartered in the Netherlands to an Alliance with locally established member NGO’s was discussed during every meeting. This important development of NLR is strongly supported and monitored by the Board. The many governance related changes for a sound transition of responsibilities were discussed at every meeting. Special attention was paid to a change in the Board in India in the first quarter, as well as an update of the Alliance Manual.

- The recruitment process of a new CEO which started in February. A profile was developed and an agency was chosen from a long list based on recommendations from other NGOs. A selection committee of three Supervisory Board members was formed as well as an advisory committee consisting of representatives of the management and Employee Representative Body. In September the Board unanimously approved the appointment of the selected CEO in an additional meeting. Linda Hummel was appointed as NLR’s CEO starting on 1 January 2021.

Further activities and decisions included:

- In March the Board approved adjustments in the investment statutes.
- In June the Board approved the 2019 Annual report and Annual accounts of LRI and in September (delayed due to COVID-19) the 2019 Annual Report and Annual Accounts of NLR.
- At its December meeting the Board approved the 2021 Annual Plans and Budgets of NLR and the LRI. Following a selection process, Noor Tromp was appointed as the successor to Paul Klatser. In addition, the health and wellbeing of the International Office staff was discussed.

In December 2020 the Supervisory Board carried out a self-evaluation facilitated by an external moderator. The moderator had access to the notes of the meetings and interviewed the Board members. The overall conclusion was that even under the challenging circumstances brought on by COVID-19, NLR is on course and that the quality of the supervision was good. The competences of the Board, the Board dynamics and the development in the quality of the meetings received a positive evaluation. With the upcoming challenges and changes in 2021, a new CEO and two new Board members, the Board will pay extra attention to:

- Make its supervisory vision and strategy more formally explicit
- Endeavour to achieve a better balance in the meetings between providing information, discussion and decision-making.



## Remuneration of the Chief Executive Officer

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

Furthermore, the Supervisory Board regards the position of NLR's CEO as more than a fulltime job. It is a role with great responsibility that requires a high profile and professional performance. It is a role with great responsibility that requires a high profile, professional performance. The Chief Executive Officer is in charge of an international organisation that raises over €10,000,000 per year, employs 39 people in Amsterdam and 200 in the Country Offices, receives the support of approximately 45,000 donors and 350 volunteers, and cooperates with many international partners, including health ministries, scientists, companies and other NGOs

Every three years the Supervisory Board reviews the remuneration of the CEO, with the most recent review taking place in 2019. The Board approved the updated job description of the CEO and concluded that the remuneration as per 2020 should be adjusted in accordance with the regulations. The regulation uses three criteria to define the maximum standards for annual incomes: size, complexity and organisational context. For 2020 the Supervisory Board calculated a total of 465 points in the BSD score (420 points in 2019), resulting in a maximum average annual income of € 141,273 (2019: €120,515). The 2020 salary of Jan van Berkel is €137.767 (€120,385 in 2019). Van Berkel donated his remuneration of €10,000 as Chair of Goede Doelen Nederland (Dutch charities branch organisation) to NLR.

The combined total of annual income, taxable allowances/additions, pension charges and pension compensation and other (future) rewards, amounted to €146,000, which remains below the maximum allowed in the regulations of €201,000 per year for 2020. For further details, see Annual Accounts of NLR.





# Partners and Collaborations

Collaboration is key to achieving zero leprosy. NLR plays a major role in the following partnerships, each of which make a substantial contribution to our mission.

## Infolep and InfoNTD

Infolep is the international knowledge centre for information on leprosy and leprosy related subjects. In 2020 [Infolep](#) attracted 21,000 unique visitors across 182 countries. The portal offers access to over 30,000 publications, 10,500 of which are open access, with about 800 publications added in 2020. In addition, [InfoNTD](#) is an online platform for sharing information, publications and tools on intersecting issues around Neglected Tropical Diseases (NTDs). Attracting 26,000 unique visitors across 195 countries in 2020, the portal offers access to over 4,800 publications, 3,750 of which are open access.

Both Infolep and InfoNTD held their first ever partner meetings to affirm the long-term support of partners and their involvement in the further development of the platforms. These meetings generated important input for the development of a three-year roadmap for each platform. The Roadmaps will provide an

overview of the main priorities to further improve the services that contribute to Zero Leprosy and cross-learning on Neglected Tropical Diseases.

In addition to investing in relationships with partners, collaboration with network organisations was intensified. A major highlight in 2020 was the launch of the new, online [Guides on Stigma and Mental Wellbeing](#), in which NLR and InfoNTD played an active role. This has increased the visibility of the platforms and has been very well received.

## Leprosy Research Initiative (LRI)

Leprosy Research Initiative (LRI) plays a key role in the strategic funding of leprosy research and in strengthening research capacity in leprosy endemic countries. NLR manages and houses the LRI team; the CEO of NLR chairs the Executives Group, LRI's highest decision-making body; NLR's Medical Director contributes to the Steering Committee; and NLR's Supervisory Board oversees the proceedings of the LRI. In 2020 a total of 22 ongoing and seven new research projects received funding support.

In the second half of 2020 the LRI Technical Officer worked on the development of the research agenda for the Global Partnership for Zero Leprosy. We welcomed two new partners in 2020: the ANESVAD Foundation and the St Francis Leprosy Guild. Unfortunately, one partner had to withdraw for financial reasons, partly as a result of the COVID-19 pandemic.

NLR's International Communication Advisor and the LRI team worked together and successfully redesigned the [Leprosy Research Initiative \(LRI\) website](#). The annual LRI Spring Meeting which was planned in an early phase of the pandemic had to be cancelled, but the call for proposals continued as planned.

## Global Partnership for Zero Leprosy (GPZL)

The [Global Partnership for Zero Leprosy \(GPZL\)](#) is a coalition of individuals and organizations committed to ending leprosy. Since its launch in 2018, GPZL has made encouraging progress. In September 2019, eight Sub Reports from the Leprosy Research Agenda were published in Leprosy Review, co-authored by NLR. The overall Research Agenda was published in Infectious Diseases of Poverty in 2020. LRI's Technical Officer was seconded to the Global Partnership to continue their work on defining the priorities for the research agenda and to help develop the implementation plan. This started in October 2020 and is expected to be ready by mid 2021. GPZL organised an online webinar in collaboration with the WHO and with the support of NLR on SDR-PEP in January 2020. A second webinar which addressed the role of persons affected by leprosy in SDR-PEP implementation was held in December.







## International Federation of anti-Leprosy Associations (ILEP)

The [International Federation of anti-Leprosy Associations \(ILEP\)](#) continues to be a key international player in the fight against leprosy. NLR personnel had a leading role in the ILEP, with NLR's CEO concluding his final year as ILEP President in October and the NLR Medical Director taking over as Chair of the ILEP Technical Commission (ITC) in November. The Technical Commission has been restructured and will be working on a series of new initiatives prioritised by people working on the frontlines of leprosy work. Several other senior NLR staff are liaising closely with ILEP colleagues in other leprosy organisations regarding programmes, fundraising and communication. NLR has been approached several times by ILEP partners to be involved in joint proposals or to provide technical support on SDR-PEP, the SkinApp, or stigma-related topics. At a very well-attended virtual ILEP conference in September, NLR staff presented digital tools and new approaches for technical capacity strengthening, which is likely to be a major focus area for ILEP in the next few years ahead.

## Dutch Coalition for Disability in Development (DCDD)

NLR's Head of Programmes chairs the Dutch Coalition for Disability in Development (DCDD) which comprises more than 20 organisations and professionals who

lobby the Dutch government for better policies for the inclusion of persons with disabilities, including those affected by leprosy. This lobbying has contributed to the large-scale funding of two partnerships of organisations that focus on disability inclusion, as well as training and support for organisations to be more inclusive in relief aid and in the education sector. In 2020 DCDD celebrated its twentieth anniversary.

## Coalition for Operational Research in Neglected Tropical Diseases (COR-NTD)

COR-NTD is a network of researchers in Neglected Tropical Diseases (NTDs). It also administers a funding mechanism for NTD research that is currently funding two NLR multi-NTD projects, one in Mozambique and one in India. The COR-NTD's annual research conference in November 2020 was held on a virtual conference platform and was attended by many participants from across the world. NLR co-organised a breakout session on NTD-related stigma and mental health to extract lessons learnt from current research projects on these topics. The session was well received. In the COR-NTD meetings' Innovation Lab NLR presented the new ILEP/NNN Guides on Stigma and Mental Wellbeing. The short intro video was very well received and has since been used multiple times during online events.

## The NTD NGO Network (NNN)

Several NLR staff continued to participate in cross-cutting groups of the NTD NGO Network (NNN) which comprises more than 80 organisations around the world. A highlight was the virtual three-day Spring Meeting of the DMDI group (Disease Management, Disability and Inclusion), with active participation of representatives from several WHO departments. The cross-cutting group on skin-related NTDs was also very active and is working closely with the WHO on developing a strategic framework for Skin NTDs. NLR's Medical Director was also involved as a member of the NNN Executive Committee. The NNN annual conference was also held virtually, and as a result it was attended by a record 500 participants. While this enabled many more NLR staff to attend this conference, we greatly missed the networking opportunities and the encouragement that comes from face-to-face meetings with colleagues working on similar topics. Nevertheless, the conference was very successful and NLR's input very well appreciated.



# Organisational Perspective

## Looking forward

Global challenges require global cooperation. Sustainable solutions and impact can only be achieved by coordinating resources and efforts in health development. Working together effectively with all actors is key. NLR is capable of initiating and maintaining partnerships on local, national and global level. Donors also play a major role in this way of working because they have large networks, expertise and experience at strategic and operational, local and global levels. NLR will continue to focus on bundling different skills and knowledge to pave the way to zero leprosy.

An important next step for our organisation is to finalize the transition of former branch offices to national, local NGOs. This re-structuring requires an ongoing investment in capacity development. NLR believes responsibility for change is best taken close to the problem, especially when the issues relate to (public) health and mental wellbeing. This requires the implementation of policies that can only be effective if they are adapted to the sensitivities of persons affected by leprosy and their communities.

A shift in focus of different stakeholders to tackling COVID-19 related issues at the expense of neglected diseases like leprosy poses a threat to NLR. There will be significant catching up to do once our work can continue unhindered by the pandemic. NLR prepares for a post-COVID period in which uncertainty of our funding position is factored into our annual and multi-annual planning. We need to learn what motivates our donors post-COVID-19, what may change in their priorities and how to keep them involved and well-informed.

COVID-19 forced us to find new ways of working, but it also brought about positive and lasting adaptation. NLR will continue to invest in its IT systems, optimise working from home and different hybrid forms (at office, home or in country) with multiple people. Working online enables us to be more inclusive.

The onset of COVID-19 once again made it very clear that the most vulnerable people and communities are overlooked in times of crisis. We therefore had to resort to emergency response efforts in 2020. But now and in the future, NLR has a duty of care. Exclusion, competition for resources, lack of awareness, profound stigma and discrimination at government and community level, all undermine social cohesion and effective leprosy control. As António Guterres, Secretary-General of the United Nations, said in 2018, “There is never a humanitarian solution for a humanitarian crisis. The solutions for the humanitarian crisis are always political ones.” In that light, NLR will intensify strengthen its lobbying and advocacy efforts in the future. Our aim is to get political and institutional commitment from changemakers for inclusion, better knowledge, awareness and protection for the human rights of persons affected by leprosy.

Lastly, we also look beyond the borders of our own sector. We keep an eye on potentially interesting innovations in different industries that may help our cause. For instance, NLR’s SkinApp is a digital solution with real-world impact that is now adopted by the WHO. Sometimes the best ideas come from unexpected angles. They can help us tackle old problems with modern solutions.



# Finances

## Result 2020 in short

The annual accounts are a consolidation of the NLR annual accounts and the Leprosy Research Initiative (LRI) annual accounts. The 2020 total consolidated income was €10,4 million (2019: €8,5 million), while €9,0 million was budgeted. Total expenses were €11,2 million (2019: €12,0 million), while €12,6 million was budgeted.

After adding the positive result from our financial investments (€0,4 million), the overall negative result for 2020 is €0,4 million (2019: €2,5 million negative result), which was subtracted from our earmarked funds and reserves. We budgeted a negative result of €3,3 million including the budgeted expenditure from earmarked reserves and funds.

[This chapter provides a summary of our finances. Please see the annual accounts for more information and details.](#)



# Financial Highlights

## 2020: income

### Overall income

Total income in 2020 was above budget and higher than last year. Income from individuals was higher than budgeted and higher than in 2019, when income from legacies was significantly lower. Once again we were happy to receive our annual contribution of €1,35 million as beneficiary of the Dutch Postcode Lottery. Our income from other non-profit organisations totalled €2,1 million. This was similar to last year, but lower than budget due to the fact that institutional donor income expected for 2020 moved into 2021. We gained €0,4 million in positive results from our financial investments.

### Fundraising in the Netherlands

In the 2020 budget we anticipated income from our own fundraising (excluding income from legacies) would increase to €2,7 million. Actual income amounted to €2,6 million, which was lower than budgeted but higher than in 2019. Thanks to our successful door-to-door campaign, the number of committed donors grew in 2020, thereby strengthening the structural income in the years to come.

### Legacies

In line with previous years, we budgeted our 2020 income from legacies at €1,4 million. In 2020 we received €3,7 million. The number as well as the average size of individual legacies exceeded those received in 2019, when we received €1,9 million.

### Dutch Ministry of Foreign Affairs

Between 2017 and the end of 2019 we received €360.900 from the Ministry of Foreign Trade and Development Cooperation under the Accountability Fund for the programme LEAP: Local Economic development of people with disability through active Advocacy for an inclusive Policy. In 2020 we recognised €67.000 as income, covering expenditure for our planned activities.

### EDCTP

In 2018 a total of almost €3,2 million was awarded by the European and Developing Countries Clinical Trials Partnership (EDCTP) for the PEP4LEP project. This multi-partner project will be implemented over a period of 52 months from 1 October 2018. In 2020 around €439.000 was recognized as income from this grant.





# Financial Highlights

## 2020: expenses

### Overall expenditure

Total expenditure in 2020 was behind budget as well as lower than last year, which was the direct result of the COVID-19 pandemic affecting our work. In 2020 we spent €9,1 million on our objectives, which was 81% of our total expenditure (2019: 84%).

### International leprosy programmes

In order to fulfil our mission, we have operations in five leprosy endemic countries as well the Netherlands. Despite our work being made more difficult by COVID-19, we have been able to spend €7,7 million on international leprosy programmes, which was lower than budget at €8,5 million.

### Information and awareness raising

Total expenditure on information and awareness raising initiatives was €0,6 million, while €0,7 million was budgeted. This is in line with last year's expenditure.

### Scientific and operational leprosy research

In 2020 €0,8 million was spent on research projects and running costs. Total expenditure was almost 70% lower than budgeted due to the impact of the COVID-19 pandemic. This was also lower than the €1,4 million expenditure of 2019.

### Fundraising

Expenditure on fundraising was €1,6 million, instead of the budgeted €1,5 million. We invested in attracting more committed donors in order to secure future growth in fundraising income that will enable expansion of our programmes in endemic countries. We continued our door-to-door fundraising with positive results.

Total spending on our own fundraising in relation to total income raised amounted to 15% (2019: 14%).

### Financial income and expenditure

The balance of financial income and expenses regarding invested reserves was €0,4 million in total. This was a very substantial increase against budget (€0,2 million), but less than last year (€1,0 million). Yield on the portfolio was 3%.

### Expenses from our earmarked reserves

We spent a total of €1,0 million from earmarked reserves: €0,3 million on transforming our branch offices into local NGOs that are embedded in their local contexts; €0,4 million on investments in our IT-operations; and €0,3 million on investments in our fundraising. We invested in transition plans for our former office in Mekong, Vietnam.

### Expenses from earmarked funds

In 2017 we received €9,4 million from the Dutch Postcode Lottery for a Dreamfund Project 'Stop the Transmission of Leprosy'. A portion that remained unspent in 2017 was placed into an earmarked fund. While the project was initially planned for a five-year period in three countries with project coordination in the Netherlands, a no-cost extension has been granted upon request, prolonging the project beyond 2021.

For 2020 activities were planned for a total budget of €1,4 million. By the end of 2020 a total of €1,6 million was spent, compared to €1,4 million in 2019. Earmarked funds at end of year 2020 amount to €5,0 million, which are due to be spent in 2021 and beyond.







# Relevant points of interest

## Consolidated annual accounts

The Leprosy Research Initiative (LRI) has been registered as a Foundation under Dutch law since 1 June 2015. The LRI represents a unique model of cooperation and coordination in the funding of research. Members of LRI include: American Leprosy Missions (ALM), German Leprosy Relief Association (GLRA), The Leprosy Mission International (TLMI) and NLR. Damien Foundation and Anesvad Foundation joined in 2020. Together, they are committed to the fight against leprosy, and to this end have combined their funding for leprosy-related research in the joint LRI fund. In 2020 effect: hope ended the partnership and has withdrawn their support to LRI due to lack of funds. NLR manages LRI operations, implementing the decisions of the LRI Executives Group, overseen by the NLR Supervisory Board. The LRI and NLR 2020 annual accounts have therefore been consolidated.

## Reserves policy

NLR has drafted a reserves policy to ensure the continuity of our work and set aside funds for the future. This policy identifies three categories: continuity reserves, earmarked reserves and earmarked funds.

Continuity reserves are kept to cover risks in the continuity of the organisation and to ensure that it can meet its obligations in the future. According to the guidelines of the Goede Doelen Nederland (Dutch charities branch organisation), this reserve can be a maximum of 1,5 times the annual organisational costs. NLR aims to have continuity reserves of between 0,5 and 1 times the yearly costs of the work organisation.

Earmarked reserves are funds that are set aside and approved by the Board for specific purposes to spend in the years ahead. Every year the balance of the earmarked reserves is re-evaluated and redetermined by Board approval.

Earmarked funds are funds received from a third party to be used for a specific purpose in the future and are therefore earmarked to be used for this purpose only.

## Investment policy

Our investment policy prescribes investments in sustainable, socially responsible and low-risk bonds and sustainable, socially responsible shares. The investment horizon is limited to a period of five years and has a defensive profile. In 2020 the Supervisory Board approved the extension of the portfolio to include micro loans as part of the policy. The portfolio bandwidth is as follows: shares 10-30%, bonds 50-90%, micro loans 0–5% and liquidities 0-50%.

The portfolio is managed by Rabobank and the investment manager checks adherence to this policy twice a year. Quarterly reports on our portfolio are shared and discussed with the NLR Financial Audit Committee



# Beyond 2020

For 2021 we are aiming to increase our income further by focussing on both individual and institutional donors. The total budgeted income for 2021 is €10,2 million.

To finance our ambitious plans for 2021 we are budgeting a total expenditure of €13,8 million. This will allow us to invest further in both our expenditure on objectives as well as strengthening our fundraising and organisational structure. Of this total expenditure €3,3 million is budgeted to be spent from earmarked reserves and funds.

In line with the Multi-Annual Strategy, projections for 2022 and 2023 are roughly in accordance with the budget for 2021.

# NLR Budget 2021

This is the approved consolidated NLR 2021 budget. For the separate 2021 LRI budget, please refer to LRI’s [annual accounts](#) of 2020.

Income	€ 1.000s
Income from individuals	4.200
Grants from governments	822
Income from other non-profit organisations	3.803
Income from companies	-
Income from lotteries	1.350
Income from allied and joint non-profit organisations	-
Income from sales of products and services	28
Other income	37
<b>Total income</b>	<b>10,241</b>

Expenses	€ 1,000s
International Leprosy programmes	9.526
Information and awareness raising	683
Scientific and operational leprosy research	1.926
<b>Spending on objectives</b>	<b>12.135</b>
Fundraising expenses	1.282
Management and administration	392
<b>Total expenses</b>	<b>13,809</b>
Financial Income and Expenses	250
<b>Balance of income and expenses</b>	<b>-3.318</b>
<b>Destination of the balance of income and expenses</b>	
Additional / Withdrawal from	
Continuity reserve	-
Earmarked reserves	-1.596
Earmarked funds	-1.721
<b>Total mutation of reserves and funds</b>	<b>-3.318</b>



# Colophon

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

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until  
**No Leprosy Remains**