

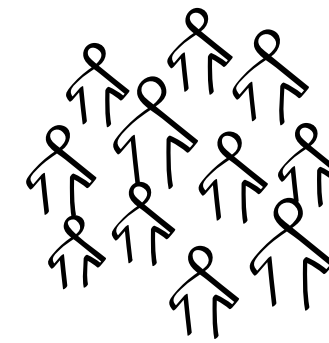


Annual Report 2021

Staying Connected

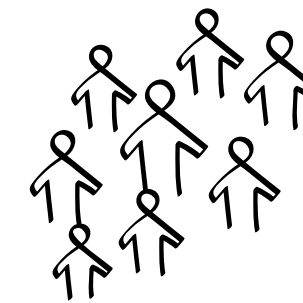
Working together to fight leprosy

1985



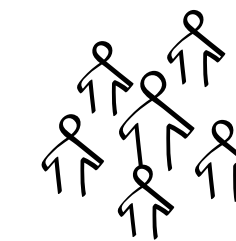
550,224

1995



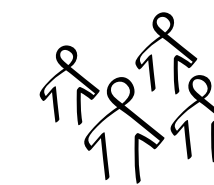
529,376

2005



296,499

2020



127,396*

Towards a world free of leprosy and its consequences

* Globally, 127,396 new leprosy cases were reported in 2020. This is a 37% reduction compared with 2019. This change reflects the reduced detection of leprosy patients due to COVID-19 control measures, which hindered access to health services. Reporting of data was also affected by the pandemic: 127 countries (out of 221) provided data in 2020 (160 in 2019).

Source: World Health Organization

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The year in review



Vision, mission, story



Leprosy: still a pressing matter



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Cooperating with institutional donors



Individual donors & Communications



Raising awareness for leprosy



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Impact on work and staff



Zero Leprosy

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Our road



Zero Transmission



Zero Disability



Zero Exclusion



Indicators



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'Stop the transmission of leprosy' project expands to Nepal



Fashion show made by persons affected



Transition into a Alliance of Members



Ready4PEP kick off in Nigeria and Mozambique



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Staff composition



Integrity



Governance



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Finances

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Financial Highlights 2021: income



Financial Highlights 2021: expenses



Relevant points of interest



NLR Budget 2022



2021 in brief

until No Leprosy Remains

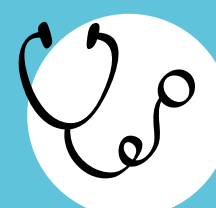
2021 was an exceptionally difficult year in many of the countries where leprosy is endemic. Due to COVID-19, progress in scaling up preventive treatment for leprosy, research projects and roll-out of innovations were all delayed. The pandemic also exposed fragile access to health and social services, especially for those affected by leprosy. Naturally, we have not been idle and, despite these delays, we are still confident that we will make up for lost time and stay on track to eliminate leprosy within one generation.

Zero Transmission



15,177

New leprosy patients detected



4,862

Health staff trained on leprosy



239,557

Persons who received SDR-PEP

Zero Disability



1,814

Health staff trained on prevention of disabilities

Zero Exclusion



894

Local actors better voicing concerns and needs



3,130

Persons affected with improved socio-economic situation



5,263

Health staff sensitised on stigma

Our highlights

New NLR study shows elimination of leprosy is on the horizon

New research shows that the cumulative number of individuals requiring preventive treatment is 40 million globally, reducing the incidence by 90% in 22 years.

Increase in individual donors and donations in the Netherlands

The donor base grew from 44,000 to over 45,000 relations, and individual fundraising is higher than the expected amount of income.

Transition into an Alliance of members

Autonomous national NGOs, with own boards and registration independent from NLR in the Netherlands.

READY4PEP kick off in Nigeria and Mozambique

Confirming the importance of the interventions and the success of the strategies used to find and screen contacts.

Technical Capacity Building in Action!

Aiming to strongly contribute to making NLR future proof in terms of technical expertise.

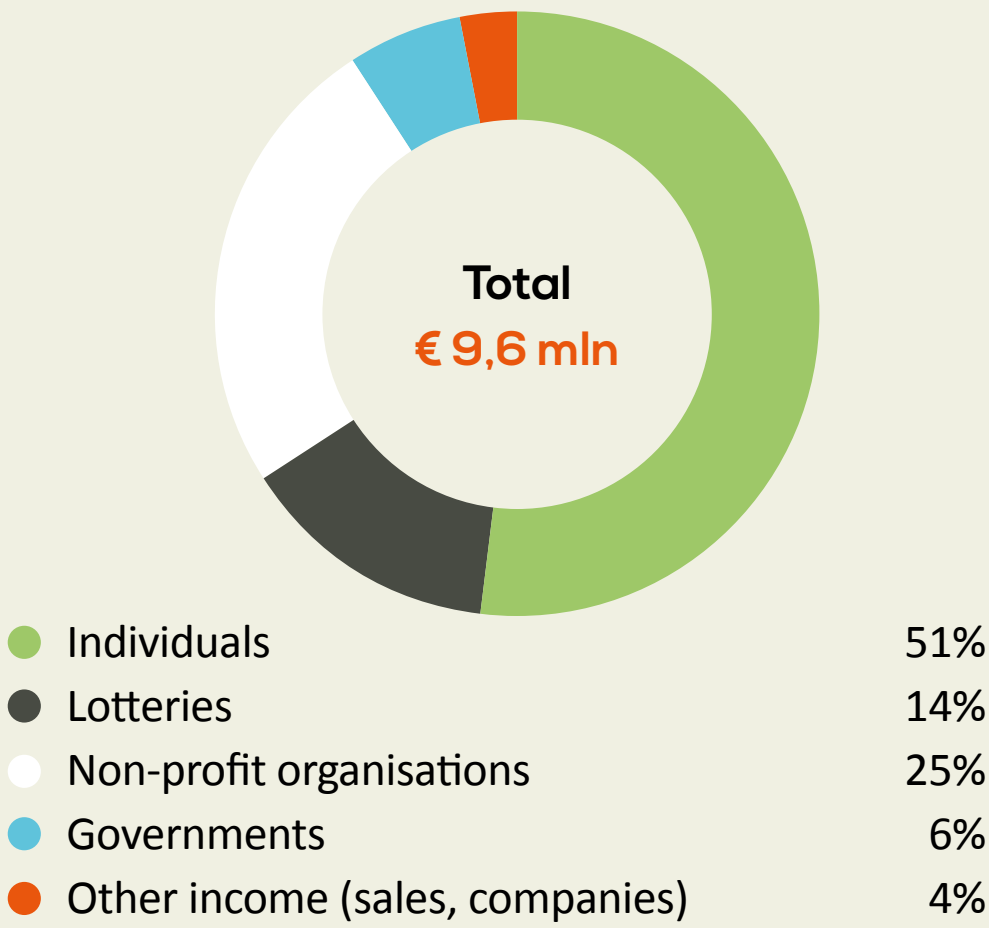
How did we spend our money in 2021?

In 2021, we received a total of €9.6 million income. We spent €9.2 million on our objectives, which is 82% 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 more than 45.000 donors and around 100 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.

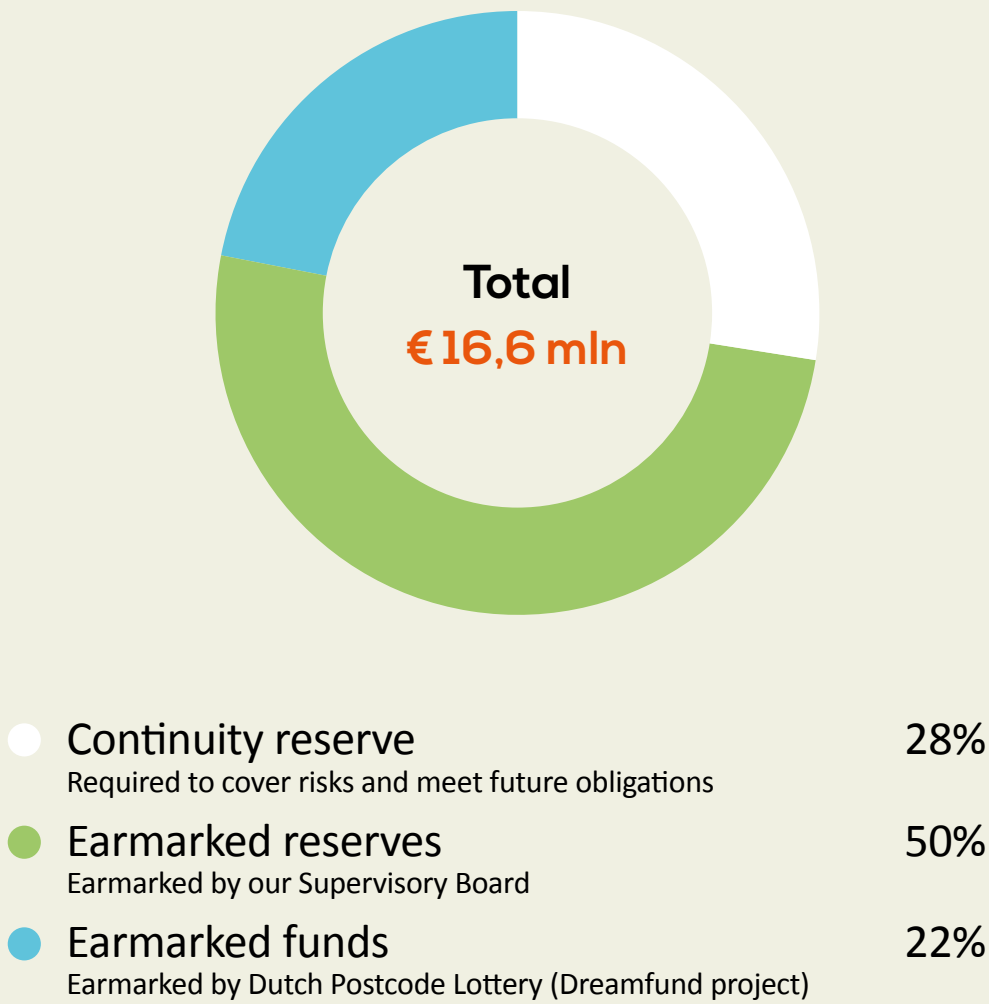
Other details concerning our income and expenses are shown in the Annual Accounts.

Annual accounts

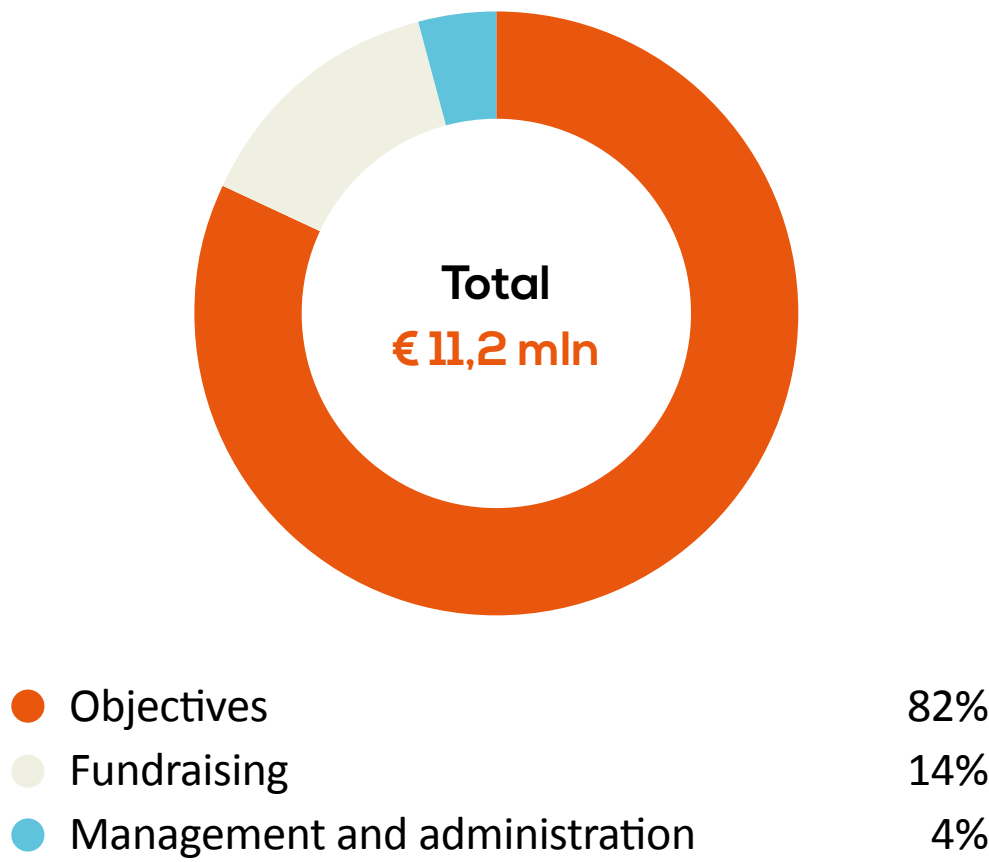
This was our income in 2021



In support of our mission, these were our reserves and funds in 2021



This is what we spent in 2021



This is what we spent on our mission in 2021



SWOT Analysis

The SWOT analysis below shows both the strengths and weaknesses of NLR, as well as the opportunities and threats on the (inter)national market.

Our organisation

Strengths

- Track record of over fifty years in evidence-based leprosy programmes.
- Leading partner in many national and international networks and partnerships related to leprosy and other Neglected Tropical Diseases (NTDs).
- Strong technical expertise combined with programmatic know-how.
- Presence in countries with highest number of leprosy cases.
- Development and implementation of innovative approaches.
- Strong reputation in the leprosy and NTD sector.
- Loyal individual donors in the Netherlands.

Weaknesses

- Lack of focus and coordination in advocacy activities.
- Not enough learning and sharing.
- Not enough expertise to raise funds in all countries of operation.
- Low brand awareness outside the 'leprosy world'.
- Limited funds and other resources in relation to number of activities and projects.
- Lack of coordination in planning.

Our environment

Opportunities

- Leprosy is a curable and now also preventable disease – the end is in sight.
- Organisations active in leprosy and related fields show interest in NLR knowledge and best practices.
- Promising research in the field of leprosy prevention.
- eHealth and mHealth (Mobile Health) solutions.
- Increased donor interest in prevention.
- Increase in legacies.
- Growth of partnerships in the field of NTDs.
- Increased global awareness around the need for strong health systems due to COVID-19.
- New generations interested in jobs with a purpose.

Threats

- Rapid decline in technical leprosy capacity worldwide: retiring leprosy doctors and health workers.
- Slow scale-up of SDR-PEP due to opposing views.
- No dedicated supply of free rifampicin available yet for SDR-PEP
- Rifampicin not registered as preventive medication for leprosy in many countries.
- Limited (governmental) resources in endemic countries, high turnover of government officials and competing demands of different NTDs or other diseases.
- Decreasing loyalty of members, donors or volunteers.
- Highly competitive fundraising market for individual donors and institutional grants.
- Increasingly critical attitude by the public and media towards NGOs.
- Backlogs due to COVID-19 and restrictive measures affecting beneficiaries.
- Increasingly competitive job market.

We are NLR



2021 in review

Naturally, 2021 was a year impacted globally by COVID-19. The situation in the countries where we work to fight leprosy differed enormously. Nevertheless, two years into the pandemic we have managed to adapt and continue to support persons affected by leprosy through our expertise and new protocols for changing crisis situations. This has contributed to our strong connections with communities, our innovative approach, motivated staff, and collaboration with our partners and other stakeholders.

Not a year goes by without its share of challenges. 2021 was an exceptionally difficult year in many of the countries where leprosy is endemic. Due to COVID-19, progress in scaling up the implementation of leprosy prevention with the antibiotic rifampicin, research projects and roll-out of innovations, were all delayed. For example, social distancing decreased the numbers of people participating in our research projects. To tackle this in our Dream Fund project 'Stop the Transmission of Leprosy!' we expanded the project to Nepal and Bangladesh in order to include enough study participants. This illustrates our adaptability. Another challenge was that impurities were

detected in the raw products used for the antibiotic rifampicin that we use in preventive treatment for leprosy. This was accompanied by distribution problems caused by the pandemic. This impacted project progress. However, we have achieved excellent global cooperation which has propelled improvements in the supply chain. This showcases the strength of the sector's network in lobby and advocacy. Furthermore, the pandemic exposed fragile access to health and social services, especially for those affected by leprosy. This motivates us even more to continue to focus on inclusive interventions. The pandemic also exacerbated the isolation and mental wellbeing of persons affected by leprosy, and we therefore take great pride in having developed a tool for basic psychological support in India.

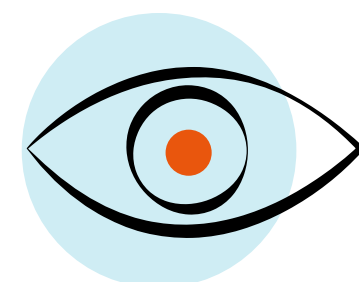
Despite delays in 2021 we are still confident that we will make up for lost time and stay on track to eliminate leprosy within one generation.

The dwindling global resources allocated to leprosy control and the decline of medical/technical leprosy expertise is a constant source of concern. Knowledge, sufficient resources, new research data and strong relationships at government level are imperative to work effectively and strategically. To increase the sustainability of our impact we must involve and connect persons affected by leprosy and changemakers in our modus operandi.

Internally we have made headway in our transition process to enable former country offices to become independent national NGOs within the NLR Alliance. Luckily, travel restrictions did not hamper this process. We were able to perform transition audits, continue qualitative checks and balances and develop capacity as planned. A historical moment took place in December 2021 when NLR Nepal completed the transition process in full and signed the first collaboration agreement with NLR in our Alliance.

Staying connected

During the crisis, NLR staff also had to overcome personal challenges. As an organisation we were affected by the loss of colleagues and family members of staff. Some staff experienced feelings of isolation due to remote working. We therefore focussed on staying connected and encouraged colleagues to keep supporting and encouraging each other, professionally and personally.



Bram van Ojik

Chair of the Supervisory Board



Linda Hummel

Chief Executive Officer

Vision and Mission

We believe everybody has the right to a dignified life and to achieve their full potential. Not just to survive, but to thrive and be hopeful about their personal future. Therefore, NLR is guided by a clear vision and mission to improve the lives of persons affected by leprosy worldwide and to prevent people from contracting the disease in the areas in which we work.

We believe that with sufficient resources, complete focus and collaboration on a global scale, we can achieve what has so far been impossible and make this ancient disease truly a part of history. We will continue until **No Leprosy Remains**.

NLR Alliance: new structure, same goal

We believe we can best pursue our mission in countries where leprosy is still endemic. In the changing global context and current phase of our work, this means further shifting ownership to NLR's Alliance members and further collaborating with the Mekong Research Centre for Inclusion (RCI) and LTR (Leprosy and TB Relief) in Nigeria. Both organisations are a valuable part of the NLR Alliance as Associate Members.

After a period of thorough preparation and a transition phase completed with an operational assessment, NLR will transfer power, responsibilities and assets to the NLR Alliance members. Staff, financing and operations of former country offices of NLR in the endemic countries will transfer to these national NGOs. The CEO of each NGO runs the operations, supervised by a local board. This new structure better reflects our vision of empowering our Alliance members to tackle national problems under their guidance. We remain united by a strong mission and vision.

Vision

A world free of leprosy and its consequences.

This is our dream. At NLR we work hard to achieve that goal and eliminate leprosy within one generation.

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.**



“Due to lack of information, I always resorted to traditional treatment, with no success. I had never visited a health unit, especially because it is 15km from my house.”

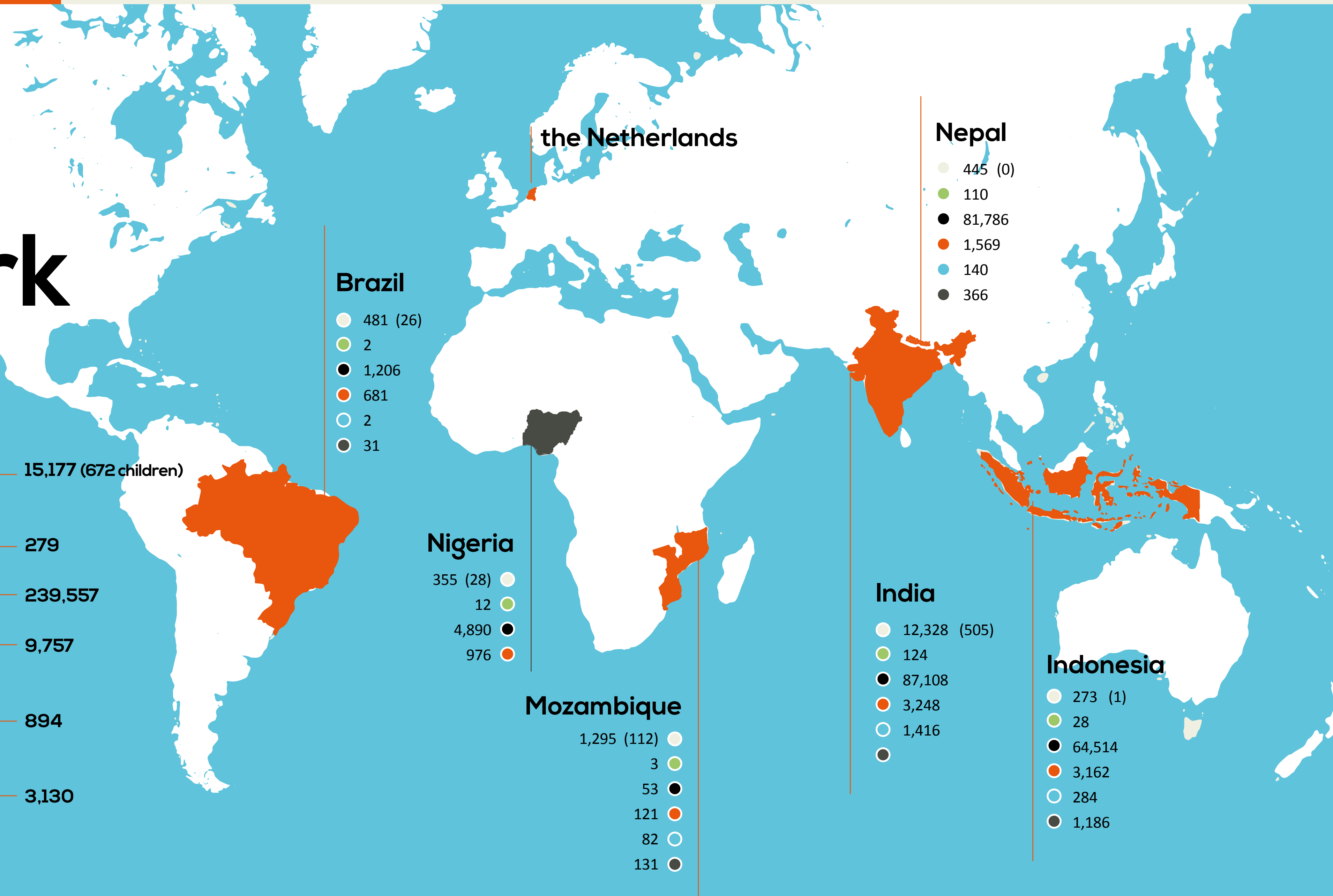
Maria Trinta, Mozambique

Where we work

In 2021

New leprosy cases detected in NLR intervention areas	15,177 (672 children)
Endemic areas with PEP support	279
People received SDR-PEP	239,557
Health staff trained on leprosy, prevention of disabilities and stigma	9,757
Local actors voicing concerns and needs of persons affected by leprosy	894
Persons affected by leprosy with improved socio-economic situation	3,130

Read about our indicators →



Leprosy: still a pressing matter

A sense of urgency

Leprosy is a poverty-related disease that still affects many families. When someone is diagnosed with leprosy, the patient and their family members are confronted with physical, social, mental and economic challenges. Leprosy may cause disabilities. Above all, it is a stigmatising disease that often leads to social exclusion, pushing people further into poverty.

2021 was an especially challenging year in dealing with the consequences of the COVID-19 pandemic. Measures to constrain the spread of COVID-19 directly affected accessibility to health care, resulting in a decrease of new leprosy patients detected by 37% in 2020.¹ The number of new leprosy patients reported in 2020 was 127,396 (202,488 in 2019). Unfortunately, this does not reflect a true reduction of transmission but instead a backlog in the identification and treatment of leprosy patients.

Undiagnosed and untreated patients increase transmission, eventually resulting in more patients and more severe disability. The percentage of children among new patients diagnosed worldwide was around 7%, similar to 2019. The percentage of new patients with visible disabilities increased from around 5% in 2019 to almost 7% in 2020.

From research to innovation to intervention

NLR aims to reduce the number of new patients and put a halt to the spread of the leprosy bacteria. That is an important reason for NLR to invest in research and innovation. Moreover, we conduct research and implement strategies to reduce discrimination, physical and mental health issues. Results and lessons learned from NLR's research projects are widely shared with the aim to be taken up in improved policy and practice by various international, national and local stakeholders.

Collaborating to combat challenges

Leprosy affects people who are already living under challenging circumstances. The COVID-19 pandemic further aggravated this negative impact. Fortunately, the pandemic gradually came under control in the course of 2021, so that most projects that were paused because of the pandemic, could be restarted. Many health programmes have suffered because of the understandable and necessary shift of attention and resources to the pandemic. A period of refocussing and catching up will be required to reinvigorate leprosy control programmes. Encouragingly, preventive treatment for close contacts of leprosy patients can now be scaled up. By doing so, the transmission of the leprosy bacteria can be slowed.

NLR's work can only be done through intensive collaboration with partners, such as the WHO, ministries of health, disabled people's organisations, universities and other leprosy organisations. 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). Within these and other networks we make a significant impact towards achieving our mission.

Together we 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.

Our work contributes to the United Nations Sustainable Development Goals (SDGs). These goals aim to ensure that no one is left behind. The SDGs provide excellent opportunities to collaborate for and with those people who are last in line. Our interventions are most closely linked to:

SGD 3 Ensure good health and wellbeing for people, including universal health coverage.

SGD 10 Reducing inequalities

SGD 17 Partnership for the goals

SDG 3



SDG 10



SDG 17



¹ The official number of new cases is reported each year by WHO around August/September. Therefore, we cannot yet provide the official numbers for 2021. It is expected that the number of newly detected cases is higher than 2020 but still lower than normal, because the COVID-19 pandemic negatively impacted case finding.

Our Donors





Despite the pandemic, a growing number of donors and partners continued to support NLR, which makes us very proud and grateful. With their ongoing support, we have managed to diagnose, treat and care many persons affected by leprosy in all three continents where NLR is active.

We highly value our supporters, partners and donors and make sure we keep them well informed and connected. Their ongoing generosity enables NLR to truly make a difference and to continue until No Leprosy Remains.



“The resilience of people affected by leprosy is admirable. Despite everything, they try to make the best of their lives.”

Peter Euser, Ambassador of NLR



“It is important that people learn more about leprosy, that it still occurs unnecessarily and what impact it can have on your life.”

Leontine Kruis, Manager Jan Kruis Museum



Cooperating with institutional donors for long term impact

Partnerships with foundations, governments, multilateral organisations and other international NGOs are crucial to achieving zero leprosy. The financial resources raised through these institutions help NLR to work towards long-term impact. As partners with complementary expertise and networks, they contribute to our mission in a broader way. In 2021 we continued working with dedicated partners such as the European and Developing Countries Clinical Trials Partnership (EDCTP), the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD) and the Dutch Postcode Lottery. We also signed new contracts with PAHO, UNESCO and Sasakawa Health Foundation, and a grant from the Leprosy Research Initiative enables NLR India to invest in an app to facilitate SDR-PEP implementation.

In 2021 NLR continued strengthening Alliance members' capacity in institutional fundraising, resulting in proceeds of nearly €1 million in 2021.

Most of the funds were raised by NLR Indonesia. In general, it was a difficult year for most of the Alliance members. This was mainly due to a lack of qualified, dedicated fundraising staff.

The main topics of the proposals receiving awards were zero transmission, zero disability and zero exclusion. With each proposal we try to get as much feedback from the donor as possible in order to continue improving the quality of our fundraising. However, due to the competitiveness of calls for proposals that we participated in, many donors do not have time to provide feedback.

Besides institutional fundraising, one of the focus points last year was setting up collaborations and knowledge sharing with institutional fundraising colleagues. A good example of this is the creation and strengthening of institutional fundraiser communities at NLR and ILEP. This enables fundraisers within the world of leprosy to learn from each other and share information, tools and best practices more easily.

The collaboration with other international NGOs has led to the development of multi-million project ideas, coordinated by NLR, which in turn have been presented to potential donors. The positive feedback received provides good reason to push forward with this approach in 2022 to realise projects and submit corresponding proposals.

Staff turnover in fundraising positions within the Alliance was one of the greatest challenges this year. This hampered capacity development and dedicated focus in this area. It also made the process of knowledge sharing within the organisation more complicated.

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 2021 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 about our cause among a broader public through various communication channels.



Dream Fund

In addition to this annual contribution, we received €9,375,000 from the Dutch Postcode Lottery Dream Fund in 2017 which 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 83% 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 25](#).



Connecting and communicating with our individual donors

Connecting and communicating with our individual donors

Thanks to the support of more than 45,000 active individual donors in the Netherlands we were able to help thousands of persons affected by leprosy in different parts of the world. Their ongoing and loyal support ensures we can work towards our mission: a world without leprosy and its consequences. The support of our individual donors is indispensable in reaching this goal.

Last year we still had to deal with the effects of COVID-19. Unfortunately, we had to cancel all face-to-face donor meetings which would have allowed for personal contact and for sharing more background information about our projects. Instead, we made personal calls to many donors on several occasions to keep them informed and connected.

On the other hand, due to COVID-19 our donors were very compassionate towards our cause because of the double burden that those affected by leprosy are confronted with. They responded well to our mailings, resulting in many - and on average higher - donations compared to last year. In total, we received €3 million from our private donors, which is €400,000 above expectations.

Because of the great success in 2020, we continued our door-to-door recruitment in 2021. However, due to ongoing lockdowns, we could only start in March, but we still managed to recruit as many as 4,100 new structural donors with this way of personal recruitment. The support of structural donors provides more financial certainty to forecast our annual structural income.

A good relationship with all our stakeholders is of the utmost importance. Therefore, we aim to tailor our communication to their needs. Four times a year we publish and distribute De Klepper, our donor magazine, which includes stories and interesting articles about leprosy and about the persons affected by it, our projects and our results. Our donor service desk is ready to answer questions personally and helps to resolve any complaints over the phone or by email.

Complaints

We take complaints very seriously and strive to address them in a satisfactory manner. In 2021 the new complaints policy and relations support system implemented in 2020 was further optimised, resulting in a much more accurate and timely response to complaints and remarks.

In 2021 we received a total of nineteen complaints. Door-to-door recruitment resulted in nine complaints, telemarketing activities generated two more, while the remaining complaints were a result of technical and financial issues. Complaints were received by phone (11) and email (8). All complaints were dealt with promptly, and depending on the nature of the complaint, either explained or investigated.

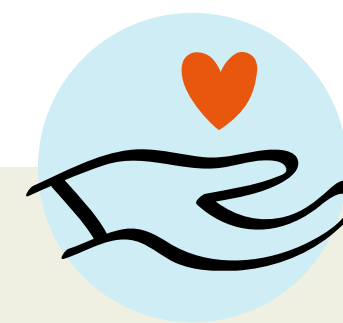




A will from the heart: charitable legacies

Last year we received €1.9 million from 73 legacies. This is €300.000 more than forecasted. Since we consider legacies to be special gifts, we feel honoured that many donors trust us to spend their legacies after they have passed away for the benefit of those affected by leprosy. Thanks to their support we were able to help thousands of people who are dealing with the effects of leprosy, exclusion and discrimination.

To inform people about the possibility of including NLR in their will, we published advertorials in several TV guides, a Dutch national newspaper (Trouw) and our own donor magazine. By using testimonials of loyal donors and interviews with experts in the field of leprosy, we inspired people to think about their ideals and how to keep them alive by means of legacies and structural donations. We also ran online campaigns on Facebook and developed tools, which helped people to think about their legacy and how to arrange this with a notary, for example.



“With my contribution, a world without leprosy comes in sight”

Wil Ottens

“As a nurse I always wanted to work in the tropics, but unfortunately it never happened. By supporting NLR, I am making up for that, somewhat. In this way, I can still help people who face infectious diseases of poverty. Because leprosy is very stigmatising, persons affected by leprosy quickly end up in social isolation. I find that heart-breaking. Fortunately, leprosy has been eliminated in Europe, but it still occurs in parts of Asia, Africa and Latin America. This feels unfair, because the disease can now be cured with medicines, and we can also prevent the bacteria from spreading further. Leprosy can and must be eliminated!

I have been a donor for eight years now and I have also included NLR in my will. My home, which includes a Bed & Breakfast, is worth a lot of money. When I die, I'll leave behind more than my daughter needs. I thought to myself: who will I give a part of my legacy to? Who can put it to good use? With enough money and collaboration, a world without leprosy is feasible in 2040. That is why I chose NLR. Through my legacy I will continue to be a donor even after my death, only then I will no longer pay per month, but in one go. It feels good that I have recorded this at the notary. Now, nothing can change it!”

Raising awareness for leprosy

Strengthening our brand in the Netherlands

We are very happy and thankful that in the past year, which was still very much affected by COVID-19, as many as 45,000 donors continued to support us. For many Dutch people leprosy is an issue far from home and a disease of the past. Therefore, it is important to underline that leprosy is still an urgent issue and that currently millions of families must deal with the devastating consequences of this disease, even today. In 2021 we kept on demonstrating the uniqueness, effectiveness and relevance of our cause and continued to raise awareness among the Dutch population.

Highlights













To raise awareness of our work with the public, we invested in the visibility of de Leprastichting, as NLR is known in the Netherlands. We ran two online campaigns, reaching almost 500,000 people. The first campaign was about the essential need for touch and hugs. During the pandemic, many people were not able to hug their loved ones, while persons affected by leprosy experience on a daily basis how people avoid contact with them and are scared to touch them. We provided tips in a digital booklet on how to get your daily dose of oxytocin - the hugging hormone - in spite of social distancing, and explained how people with leprosy are deprived of physical touch for a very long time. The booklet was downloaded 1,265 times.

The second campaign involved an online article about the negative effects of the pandemic on the spread of leprosy in India. This campaign was published in Trouw and the Volkskrant, two major national newspapers in the Netherlands. We also ran an ongoing advertising campaign in local newspapers, to raise our brand awareness among the Dutch population.

We frequently shared stories, photos and videos of persons affected by leprosy on social media. This resulted in higher numbers of followers on all channels. In addition, our digital newsletter and donor magazine ‘De Klepper’ connected our growing number of subscribers and donors with our work and mission to end leprosy.

Free publicity is a good way to generate visibility and to strengthen our brand. In 2021 we issued two press releases: one focused on the appointment of Linda Hummel as our CEO, and another about the elimination of leprosy. Unfortunately, these press releases did not create much media attention. Therefore, in 2022 we will pilot a different approach towards this potentially very useful way of connecting the urgency of our work with our audiences.

Leprastichting: Online channels in 2021

	2020		2021
 Followers on Facebook	2.062		2.253
 Followers on Twitter	1.425		1.443
 Followers on LinkedIn	580		722
 Unique website visitors	101.302		89.458
 Youtube views	163.100		15.250
 Newsletter subscribers	Dec 4.400		Dec 4.905

Results Leprastichting/Dutch website and social media



Strengthening our brand internationally

NLR is regarded as a valuable and trustworthy brand by funders, governments and implementing partners within the international field of leprosy. Our core brand values deserve to be well known and appreciated inside and outside NLR. We believe that a strong NLR brand is a key driver in our ultimate goal of achieving a leprosy-free world. Perceptions of our technical capabilities, 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.

Visibility

In 2021 we continued to invest in social advertising to generate more visibility. This resulted in a substantial increase in traffic to our international website and followers on our Twitter and LinkedIn channels. Effective communication starts with quality content. COVID-19 worked as a catalyst to start collaborating more with professionals based in leprosy endemic countries. We worked with a photographer in Nepal to collect photos and stories from those affected, with excellent results. We will continue to do this in the future. Blogging is [another new way in which to showcase our expertise on different topics](#). A first [blog post](#) in December on the ethicality of booster doses resulted in broad visibility, comments and new followers.



Campaigns and publications

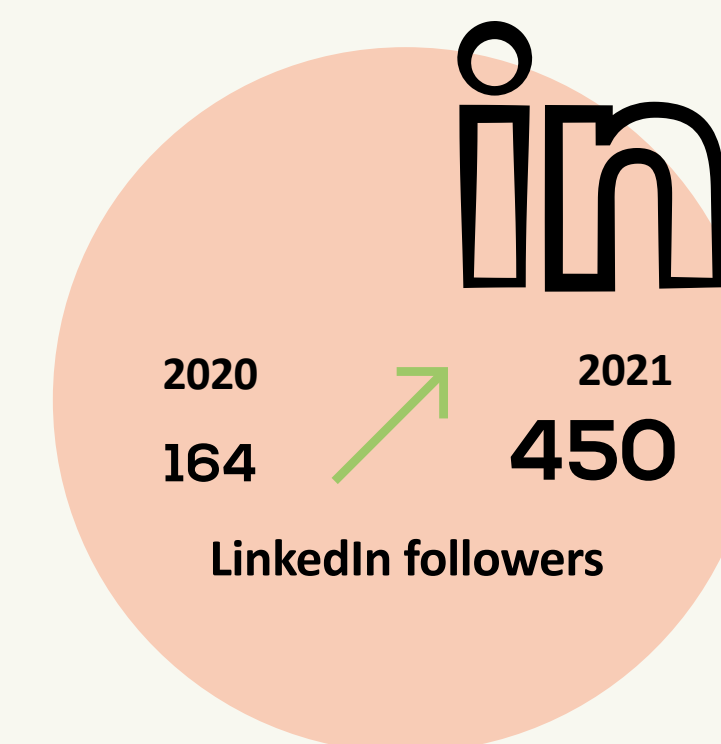
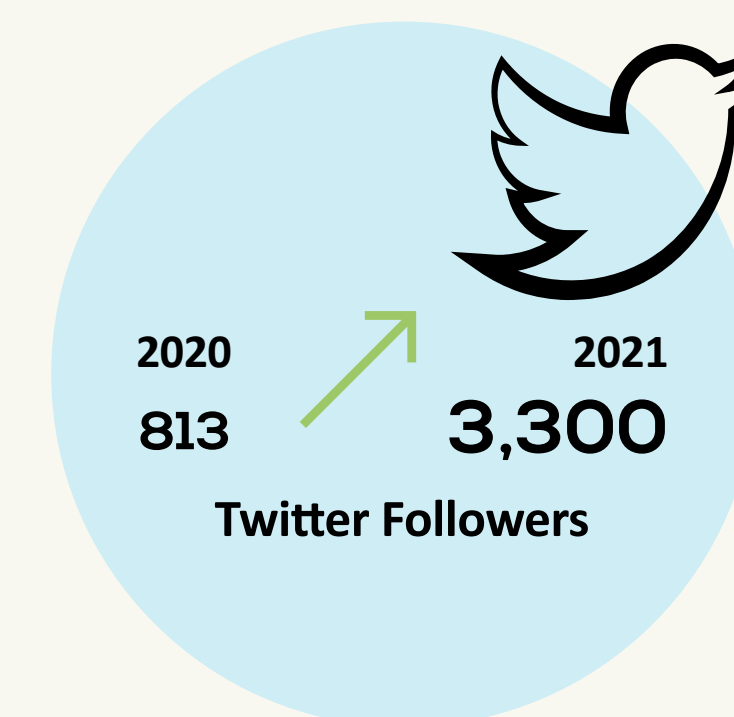
Following the WHO’s new roadmap for eliminating NTDs, in September the Guardian newspaper, together with Mediaplanet, launched the global Neglected Tropical Diseases campaign. NLR partnered in this campaign and we were featured on the digital platform with an article entitled '[On the road until no leprosy remains](#)'. The article reached 2,500 readers in our target audience (people working for institutional donors, NGOs in the development/humanitarian sector, Ministries of Health, social services, WHO, etc.) in leprosy endemic and donor countries across the world. This was a new way to raise awareness of our brand among important audiences, working together with an interesting media partner. It is hard to establish the true value of this media reach, but it will be evaluated in 2022 if it is worthy of continuation.

For World Leprosy Day 2021 a journalist from Thomson Reuters Foundation interviewed NLR Indonesia Country Director Asken Sinaga who was cited in this [article](#) on the impact of COVID-19 on persons affected by leprosy.

In 2021 three international press releases were issued through an international press distribution, which led to about 100 external publications. Our goal was to issue five press releases with 500 external publications. In 2022 a new approach involving more personal contact with journalists will be tested as this proved successful in 2021. The press release for a new NLR and Erasmus MC study showing the potential impact of preventive treatment if it is widely implemented led to an in-depth interview with NLR India’s Country Director. Express Healthcare, the number one Business News Magazine for the healthcare industry in India, published an [article](#) (p. 37-39) on the country’s strategies and interventions towards zero leprosy over the last decade.

Overall, we managed to stay connected with our audiences. Through various campaigns and initiatives and by finding resourceful solutions for COVID-19-related challenges, such as gathering stories and content from persons affected by leprosy despite of severe lockdowns, we successfully managed to engage with a growing number of people and to inspire them to work together on our vision: a world without leprosy and its consequences.

NLR: online channels in 2021



COVID-19



COVID-19 continued to impact our work and staff

Even though many countries launched their vaccination campaign in early 2021, the COVID-19 pandemic continued. In the countries where we work, new lockdowns prevented field activities, travel restrictions hampered project visits and health systems remained under severe pressure. Fewer health staff were available for leprosy prevention and control activities as they had to focus on the prevention and care of COVID-19 patients. This led to additional challenges for leprosy patients in need of medical care and caused difficulties in the implementation of NLR supported programmes. Naturally, NLR staff were also personally affected by COVID-19. Many employees tested positive, and we are deeply saddened by the loss of colleagues and staff family members.

Delays in programmes

Our '[Stop the transmission of leprosy!](#)' project is one of the projects that has been seriously delayed due to the COVID-19 pandemic. Major outbreaks in India, Brazil and Indonesia resulted in lockdowns, which were the main reason for this delay.

Furthermore, the pandemic continued to affect the manufacturing and distribution of medicines, including rifampicin, a component of leprosy treatment which is also used as preventive medicine for leprosy. These constraints in the global medicine supply chain caused further delays for some of our projects, especially for [PEP4LEP](#) and [Ready4PEP](#).

Impact for persons affected by leprosy

The COVID-19 pandemic clearly showed once again that persons affected by leprosy are last in line. New lockdowns continued to constrain accessibility to health services. Additionally, vaccination campaigns and COVID-19 care led to less availability of health staff. Therefore, key activities for early diagnosis, prevention of disabilities, rehabilitation and mental healthcare continued to be interrupted, leaving those affected by leprosy even further behind.

The roll-out of vaccination campaigns in low-income countries was not as fast as in other parts of the world. By the end of 2021, only 6% of the population in low-income countries had received at least one COVID-19 vaccination. In addition, persons affected by leprosy were not included in priority groups for COVID-19 vaccination and often have limited access to healthcare services, including vaccination sites. This increased the vulnerability of those affected by leprosy and often resulted in a double burden for those who contracted COVID-19.

In addition, many persons affected by leprosy, who are often without a safety net and living below the poverty line, lost their jobs. As Dr Tahir Dahiru, Executive Director of the Leprosy and Tuberculosis Relief Initiative Nigeria ([LTR](#)) comments, “**Many persons affected by leprosy have lost their jobs and other sources of livelihood, people were confined to their homes because of the lockdowns and other restrictions.**”

Despite the challenges and the fact that leprosy is a neglected disease, NLR will stay connected to our core mission and meet the needs of persons affected by leprosy. We have been able to persevere together through (digital) innovations, advocacy, lobbying, and a high degree of flexibility.



Zero Leprosy



Our road to Zero Leprosy

To achieve our vision of a world free of leprosy and its consequences, we believe all aspects of the disease and its related challenges need to be addressed. In working towards Zero Leprosy we will focus on three strategic programmes: Zero Transmission, Zero Disability and Zero Exclusion.

With interventions targeting at **Zero Transmission** of leprosy, we aim to prevent new infections. We mainly focus our efforts on early diagnosis and treatment of those affected by leprosy and administering preventive medication to their close contacts to avoid people who have been infected developing the disease and spreading it to others in endemic areas. Early diagnosis is important to start treatment before disabilities arise and to stop transmission as soon as possible. A patient who starts treatment is no longer infectious after a few days.

With our **Zero Disability** initiatives, we support people who are diagnosed with leprosy to prevent the development of disabilities and the worsening of the existing ones, by linking them to adequate health care and to their communities. We connect them with others who are affected so they can also receive peer support, learn about self-care, deal with the side effects of the treatment, and transform the challenges of leprosy into an empowering experience. We train peers, health workers and volunteers to counsel persons affected by leprosy to support their emotional and psychological journey and contribute to their mental wellbeing.

Social exclusion is a common experience for persons affected by leprosy. Many are pressured to leave their families, workplaces and communities. More than 100 discriminatory laws are still in place globally, preventing those affected by leprosy from fully enjoying their human rights, such as access to basic health services.

Through our **Zero Exclusion** programme we promote inclusive societies. Social exclusion reinforces a cycle of fear and stigma, late detection, disability, isolation, and continued transmission of the disease. By raising awareness we can tackle the ungrounded fear and stigma associated with leprosy. Zero Exclusion projects connect those affected by leprosy with organisations of people with disabilities, authorities, community groups and members. This ensures they are not discriminated against and have the opportunity to study and work, influence policies and live connected lives within their societies.

Acting on all these aspects accelerates our path towards Zero Leprosy. For example, we observed that the presence of strong health services and the introduction of a preventive drug have positive effects in raising hope, reducing the fear of negative consequences and therefore stigma.



Zero Transmission



Our Focus

NLR wants to contribute to stopping leprosy transmission. We can see a very slow decrease in the number of new patients detected annually, but this trend needs to accelerate in order to reach our goal of Zero Leprosy by 2040. NLR has been involved in finding evidence for the effectiveness of preventative medication, [SDR-PEP](#), and in finding feasible ways to integrate prevention into leprosy control programmes.

Before SDR-PEP is administered to contacts of leprosy patients, they are screened to see if they have leprosy, in which case they will receive the full leprosy treatment. Screening of contacts before SDR-PEP is administered helps detect new patients early before disabilities have developed. SDR-PEP kills most of the leprosy bacteria in people who have been infected but have not yet developed the disease. By killing the bacteria at an early stage, leprosy is not only prevented, but the risk of further transmission is also diminished.

What we do

NLR advocates for the scale-up of SDR-PEP implementation. The WHO has recommended the implementation of SDR-PEP since 2018. NLR supports partners in endemic countries in the take up of SDR-PEP distribution as part of their routine activities by providing technical advice and sharing practical tools and lessons learned.

There are several large, international, NLR coordinated projects that explore ways to further improve early case finding and the implementation of preventative treatment for leprosy in various contexts. In addition, we study a new regimen to improve the preventative effect. NLR also coordinates the development of a practical tool to support programme managers in selecting the most appropriate approach for SDR-PEP implementation.

Zero Transmission



Flagship projects

Stop the Transmission of Leprosy! Project (PEP++)

Financed by the Dutch Postcode Lottery's Dream Fund, the 'Stop the transmission of leprosy!' project – also known as 'PEP++' – continued work on a new package of approaches to achieve the target of Zero Leprosy. This includes a randomised controlled trial to test the effectiveness of a new preventive treatment with multiple doses of clarithromycin and rifampicin in field settings.

A major step in 2021 was the expansion of the research project to two more leprosy endemic countries – Bangladesh and Nepal – in addition to the original three countries that have the highest leprosy burden in the world: India, Brazil and Indonesia. This change was necessary because of ongoing delays caused by the COVID-19 pandemic, as well as the need to complete the field trial as quickly as possible. NLR will soon be working with its partners to recruit close contacts of persons affected by leprosy into the study in five countries.



Over the last few years, the study team has become adept at finding new ways to make progress regardless of the difficulties they encounter. Some highlights of the project include:

- Completion of the time-motion study (timing the duration of all procedures for visiting one index case and one contact) in Brazil that started in 2020 but was delayed due to COVID-19. There were several lessons learned that led to improved numbers of close contacts listed per index case and a lower percentage of contacts refusing to participate.
- Project teams in both India and Indonesia developed strong advocacy campaigns to strengthen ties with governmental stakeholders to gain final project authorisation from national regulatory agencies.
- The community education and behaviour change (CEBC) and mapping interventions were further tested and refined in the original countries. Most preparatory work on these tools has also been carried out in Bangladesh and Nepal.
- Ethical approval was already obtained for the study in Nepal. The Nepal team is keen to get the full project staff in place and begin the study as soon as possible.
- The first of the project's doctoral students completed her degree in October with multiple articles produced on the outcomes of this study.



Zero Transmission

Flagship projects

PEP4LEP*

PEP4LEP is a research project that aims to identify the best approach (community-based skin camp intervention compared to a health centre-based intervention) for screening people at risk of developing leprosy and administering preventive treatment in Mozambique, Ethiopia, and Tanzania. In all three PEP4LEP research countries, a total of 30,000 contacts of leprosy patients will be screened for various skin diseases and treated preventively for leprosy.

Project partners in PEP4LEP include four knowledge institutes (Erasmus MC the Netherlands, Lúrio University Mozambique, CUHAS University Tanzania, AHRI Ethiopia), the German Leprosy and Relief Association, and the Ministries of Health in Mozambique, Ethiopia and Tanzania.



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, grant number 707.19.58).

In 2021 the project continued to face some challenges because of COVID-19, including delays in the import of rifampicin. Despite this, the project team is proud to share the following results:

- Over the three countries, 5,003 contacts of leprosy patients were screened for leprosy and other skin diseases. Of these contacts, 4,440 received SDR-PEP.
- In 2021, 47 new leprosy patients were detected through the PEP4LEP project.
- Of all contacts screened in 2021, 2,608 people were diagnosed with other skin diseases. These contacts received free topical treatment for their skin condition or were referred to more specialised care.
- In total in 2021, 140 health workers received training on screening for leprosy and other skin diseases and administering SDR-PEP.



Zero Transmission



Flagship projects



From the field

“Now there is hope. Leprosy can be debilitating and disfiguring, but leprosy is curable and now even preventable. This project shows that this intervention is for the community, and we are all stakeholders.”

Dr. Suleiman Abdullahi,
Medical Advisor LTR Nigeria

Ready4PEP

In this second year of the project, activities were once again hampered by periods with COVID-19 restrictions. The delay in delivery of SDR-PEP continued until June 2021 when the product was finally imported in both countries.

In Mozambique a further delay in activities occurred when the Ministry of Health demanded the administration of SDR-PEP, which is not a registered medicine for leprosy in the country, to be considered a research project and therefore subject to ethical approval. That is why the first SDR-PEP handout in Mozambique took place towards the end of the year. District and province health staff received refresher training and follow up active case finding activities resulted in an average 50% increase in new cases compared to last year. This indicates the high number of hidden leprosy-cases and the difference a trained health workforce can make. Six self-care groups were revitalized and a manual for their set-up and training was written. Regular contact and collaboration between ILEP members also brought AIFO on board for joint advocacy on SDR-PEP introduction. As a result, the Roadmap to Zero Leprosy for Mozambique now includes SDR-PEP.

In Nigeria the project took off at full speed after the official launch of SDR-PEP administration at the beginning of July, with contact tracing and SDR-PEP administration in all 12 local government areas. As the baseline indicated a dwindling capacity of health staff at all levels, a series of trainings was conducted reaching 386 health workers. Five self-care groups were created - none of which existed as recorded at baseline. New behavioural change communication material was developed for community work. The toll-free telephone line of the tuberculosis media centre is now also available for all questions related to leprosy. All these innovations provided a boost to the leprosy programme in the country. In addition, joint ILEP advocacy activities resulted in the revision of the National Guideline for tuberculosis, leprosy and Buruli ulcer, now including SDR-PEP and combined self-care groups. Approval of this guideline is one of the three main outcomes defined for this project.





Zero Disability

Our Focus

Leprosy can cause lasting nerve damage and physical disabilities, including blindness and impairments to hands and feet. NLR focuses on preventing the development of disabilities or worsening of existing conditions, promoting early diagnosis, adequate treatments and self-care. We also focus on ensuring the mental wellbeing of people diagnosed with leprosy. Many of those 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. Mental illness is a debilitating factor, potentially impacting people's day-to-day life in the long term.

What we do

In 2021 we continued strengthening health systems to diagnose leprosy patients early and provide adequate support and care to persons affected by leprosy during and after treatment. We piloted approaches, trained health workers and lobbied authorities for better services to prevent disabilities. We expanded our advocacy and capacity building efforts to larger geographical areas. In addition we engaged persons affected by leprosy to learn and practice self-care, report complications, and ask for assistance devices or reconstructive surgery when they need it. Another successful mechanism that we have continued to support in several contexts is the creation and activation of self-care groups. These groups can also include persons affected by other diseases and they support individuals in the management of the disease, its treatment, and its consequences.

In the last few years we conducted research and piloted approaches in support of the mental wellbeing of persons affected by leprosy. For example, we have started to integrate this aspect within the self-care groups, experimented with approaches for psychological peer support, and supported health workers in developing their counselling skills. However, the possibility of conducting group meetings in 2021 was challenged in many countries by the restrictions related to COVID-19.



“I am happy to be here at the hospital. I have participated in lots of activities organized by NLR Indonesia such as reproductive health education, healthy eating pattern and how to manage stress. I have also been trained to talk about reproductive health topics to my peers with disabilities. I am getting more confident to speak up and express my opinions.”

Gebi, Indonesia



“Now I can talk about it, I smile while I am telling this. A few years ago, I would cry if I told this story.”

Kendrick Melo (24), Brazil

Zero Disability

Flagship Projects

Health services in Mozambique for people with a disability due to leprosy, lymphatic filariasis and Konzo

In 2021 we concluded a study in Mozambique within two districts in Nampula province, in collaboration with the Eduardo Mondlane University, the Ministry of Health and the Ministry of Gender, Children and Social Action. Information was collected on where people with leprosy, LF and Konzo live, how their disability influences their life and what services and policies are in place. These data are used to improve policies and take action to strengthen the required services. These services need to be aligned with needs of those affected themselves. Data were collected at district level using different (participatory) tools and in-depth interviews were held with policy makers and health staff at national and provincial level. Data collected at district level provided a great deal of relevant information on (the lack of) availability of health, rehabilitation and social services, and revealed how persons affected not only have to deal with their physical

disability, but also their mental wellbeing, by restrictions in participation and as a result of stigma. These data, together with the information from in-depth interviews, were analysed and further discussed in a meeting with all relevant actors, from national to district level. During this meeting a policy brief and specific action plan were developed. These two important outcomes of the study give clear guidance and can be used for immediate and more long-term improvements for persons affected by these three disabling diseases.

NLR in Mozambique will continue advocacy to ensure that the results of this study will be used. In our own interventions NLR will take a more integrated approach to self-care groups, with mental health, stigma and exclusion addressed at group and individual level. This includes training of volunteers able to assist people with mental impairments.

This work received financial support from the Coalition for Operational Research on Neglected Tropical Diseases, which is funded at The Task Force for Global Health primarily by the Bill & Melinda Gates Foundation, by the United States Agency for International Development through its Neglected Tropical Diseases Program, and with UK aid from the British people.



Zero Disability

Flagship Projects

“NLR India supported me a lot. They trained me on self-care techniques for eyes, hands and feet to prevent them from further damage. Now I am practicing these exercises regularly at home and have started gaining sensation and strength. I am really feeling good and will keep doing these exercises. They also informed me about the details of the government disability pension scheme. They regularly support me in getting medicines like eye drops, goggles, and counselling”

Mehroonisha (38), India

Basic psychological support in India

Despite the recognition of the impact of leprosy on the mental health of patients and their caregivers, few studies have been undertaken to document the level of stigma, mental wellbeing, and burden of depression caused by leprosy. In 2021, together with the Banaras Hindu University, we began such a study in two districts of two states (Uttar Pradesh and Jharkhand) in India. The study focuses specifically on people with a disability due to leprosy or lymphatic filariasis (LF). In the two districts we found and interviewed 1,454 people with leprosy-related disabilities and 10,355 people with LF-related disabilities. Of these, we interviewed 201 with leprosy-related disabilities and 240 with LF-related disabilities in more depth about their knowledge, attitudes, and practices around LF and leprosy, stigma level, mental wellbeing, and social and work participation. We found that 41% of both people with leprosy and LF-related disability had moderate or severe participation restrictions compared with only 6% of the community members; 45-50% of those affected had low mental wellbeing compared to only 14% of the community members; and 38% and 32% of people with LF and leprosy disability respectively had moderate or moderately severe depression compared to no one in the community.

These figures show that on average people with leprosy and LF in these areas are much worse off in terms of mental wellbeing and participation than the overall population. Access to mental health services is, however, still scarce.

Acknowledging this huge gap, we developed a tool for basic psychological support in English as well as Hindi. The tool is based on the Psychological First Aid kit developed by the WHO and is designed as an easily accessible peer-counselling method to reduce stigma and improve mental wellbeing and social participation among persons affected by a neglected tropical disease such as leprosy. A first ‘proof of concept’ was carried out for which 15 peer counsellors were trained to counsel persons affected. Counselling started in 2022 and the first results look very promising. However, it will require a positive assessment later in the year before this basic psychological support can be implemented on a wider scale.

This work received financial support from the Coalition for Operational Research on Neglected Tropical Diseases, which is funded at The Task Force for Global Health primarily by the Bill & Melinda Gates Foundation, by the United States Agency for International Development through its Neglected Tropical Diseases Program, and with UK aid from the British people.



Zero Exclusion

Our Focus

Persons affected by leprosy are often deprived of fundamental human rights, excluded from the social and economic life of their communities and cannot access basic services. NLR focuses on addressing the multiple factors contributing to this situation: discriminatory laws and regulations, barriers due to impairments caused by the disease, stigma from family, community members, and unfortunately even health workers. In addition, persons affected by leprosy often experience feelings of low self-esteem and self-worth which can exacerbate isolation. NLR also pays attention to other social characteristics that interconnect and can contribute to worsening exclusion, such as gender, ethnicity, poverty, and education.

What we do

In 2021 Alliance members continued to empower those affected by leprosy and strengthen their groups and associations so that they could drive change. NLR has also engaged partner organisations and several social actors to work towards disability-inclusive community models. We have also supported economic empowerment and business development initiatives to break the vicious cycle of leprosy, poverty and exclusion. Persons affected by leprosy are often part of or work closely with organisations of people with disabilities. This enhances the impact of advocacy and lobbying efforts for more inclusive laws and policies. To make sure that international treaties such as the UN Convention on the Rights of Persons with Disabilities and the UN Principles for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members are applied at local scale, we continue working with other ILEP organisations and the broader International Disability Movement to strengthen our (inter)national lobby. However, in 2021 the COVID-19 pandemic has continued to have a negative impact on social isolation, economic opportunities and access to services of persons affected by leprosy.

“ The leprosy that infected me also affected my girls. They told me they were often teased, despised, and made to cry by their school mates. My girl’s bag was taken by force and some books were torn. ”

Ms Indrawati Ratmadja, Indonesia

Zero Exclusion

Flagship Projects

Socioeconomic rehabilitation project in Brazil

In Brazil we support members of selfcare groups to develop small business initiatives. A successful project is taking place in Rondônia State, where women produce and sell bio-jewels made with natural products, including nuts and seeds from the Amazon area. This project enables entrepreneurship, positively contributes to the participants self-esteem and increases their financial independence. In the last two years, support and training, including for new members, often had to take place virtually due to COVID-19 restrictions. In 2021 efforts attempted to make this project more sustainable. Support for the producers to sell their products at local fairs continued, but online sale was consolidated by setting up an Instagram page. Attention to new marketing strategies will be important in 2022. Ten women were officially recognized in their profession as craft workers by receiving an artisan licence valid for

the whole country. The end of the year even saw a large promotion event taking place. Local government provided the opportunity to sell the bio-jewels for a week in a shopping centre and organised a high profile [fashion show](#) where the female producers could wear their products. This event was covered on television and through other media at national level.

Although support for economic activities is key, all other aspects related to self-care and mental health of the group members are maintained. As some women expressed: “We are more than a diagnosis, we are people, artists and businesswomen. Our resilience has increased.” Support for income generation in a context of poverty is essential. There is also a clear need and willingness at governmental level to expand this experience to more locations.



Zero Exclusion

Flagship Projects

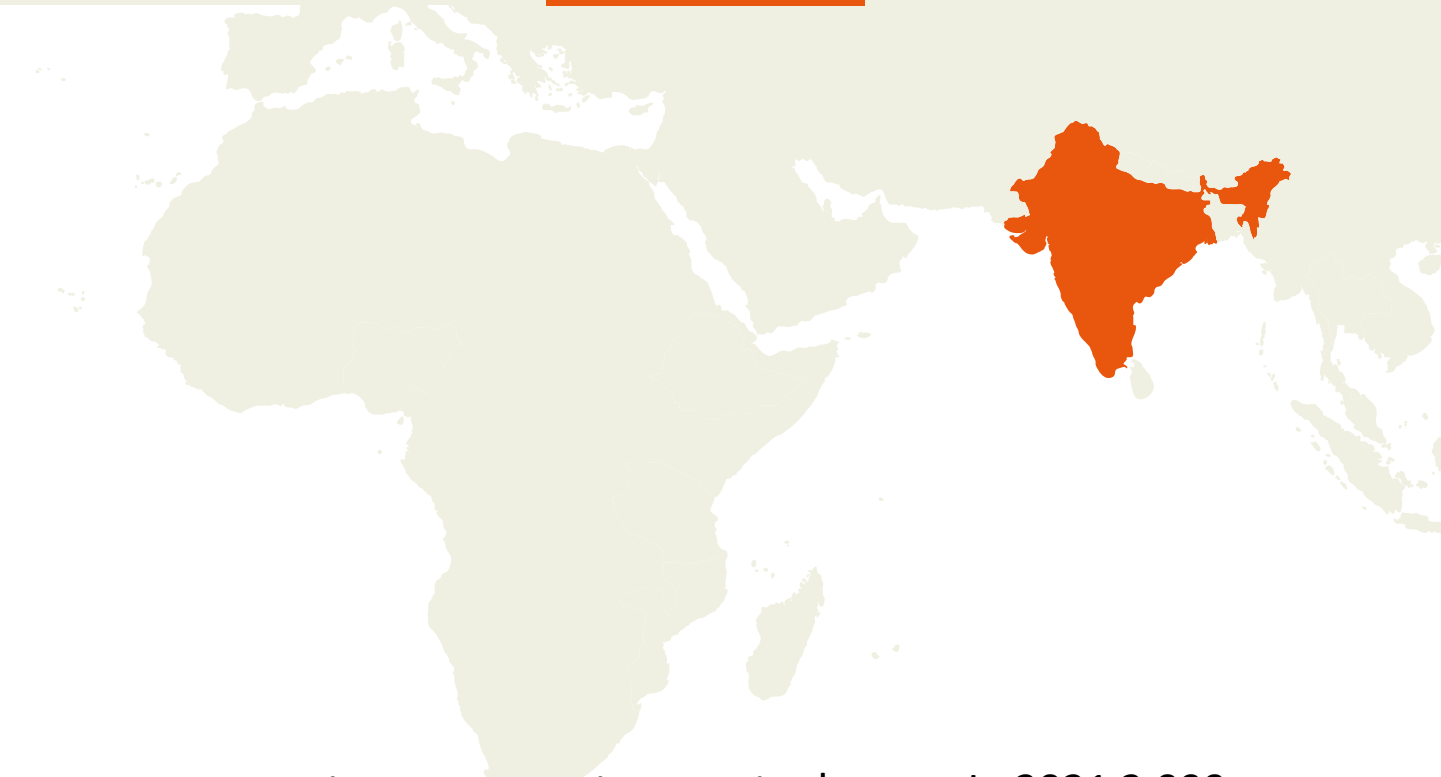
Empowering persons affected by leprosy or a disability in India

This project seeks to empower persons affected by leprosy and/or a disability by facilitating their involvement in community based peoples' institutions and strengthening these institutions in various ways. Besides the formation of self-help groups for enhanced livelihood opportunities, the groups together with organisations of people with a disability raise their concerns via existing networks and are helped to speak up for their rights and entitlements to decisionmakers in the health, social welfare and education sectors.

During 2021 the existing 290 self-help groups continued to mobilise their resources (rotating saving and credit among group members) and use this for micro enterprises. Interesting examples include the start-up of a coaching centre, the production of combs for sale, and the purchase of an auto-rickshaw to carry passengers for a fee. This year there was also progress in terms of linking three self-help

groups to government support schemes. In 2021 2,099 people applied for and received assistance and protective devices and 54 persons affected by leprosy or a disability were linked to vocational training opportunities. 15 people were directly supported with micro-credit for their livelihood. 252 were able to apply to government schemes and services and receive special identity cards for people with a disabilities and pensions, or free passes for bus or train travel.

In 2021 the COVID-19 pandemic hampered field mobilization ambitions. We planned to set up 60 new self-help groups in 2021. In the end we could only form 10, although they are functioning well, and the members are learning and attending regular meetings. They are also engaged in saving money and inter-lending. Efforts to facilitate more groups are continuing in 2022.



Indicators

We aim to monitor, evaluate and learn from our projects in order to understand the extent to which we are progressing towards Zero Leprosy and to adapt our approaches to enhance our impact where necessary. To achieve this we use a set of standard indicators and a variety of customised indicators that enable us to gauge the implementation of our projects and the achievement of our targets and milestones.

We complement these indicators with qualitative information to understand how our actions change services, policies, behaviours and attitudes. We aim to further expand our capacity and the quality of our monitoring and evaluation system and continuously use the information gathered to inform our future actions.

New leprosy cases are detected and reported both by health workers trained and supported by NLR and employed in health systems and by specific activities conducted by NLR and its partners.

In 2020 and 2021 we have in general reported a lower number of new leprosy cases. Unfortunately, this is not due to reduced transmission of leprosy, but mainly to the negative impact of COVID-19 on health systems: many health workers and resources were re-directed to COVID-19 related activities and people were less able to access health care for other services and diagnoses. A high number of cases were detected in areas where we implemented an active-case finding strategy using community campaigns. These cases already existing in the community remained undetected for a long time. These findings will inform NLR's future plans.

One of the key strategies we are promoting to stop the transmission of leprosy is the adoption of SDR-PEP as an integral part of leprosy programmes. Despite the challenges due to COVID-19, in 2021 we have increased the number of **contacts that received SDR-PEP** and the number of areas (districts, provinces, municipalities) **where SDR-PEP was introduced**.

However, we are progressing more slowly than planned, partly because the introduction of a new drug and the related programme activities require additional advocacy and technical assistance efforts. We are also expanding gradually to collect and apply what we learn in a limited number of areas in order to improve our impact when scaling up.

We focus on **training health workers** to improve their competencies. In 2021 we trained 9,757 health staff in leprosy diagnosis, treatment and SDR-PEP, and to prevent disabilities of persons affected by leprosy. We also sensitised them to issues of stigma. Some training sessions were postponed because of COVID-19-related restrictions, but we were able to reach many health staff by experimenting with e-learning.

We also work to **engage** locally relevant organisations, communities and institutions (**local actors**), for example, self-help groups, Organisations of People with Disabilities, media, village committees and local groups. We sensitise them to issues of stigma and support them in taking action **to voice the rights and concerns of persons affected by leprosy** so that they can contribute to more inclusive societies.

In 2021 we worked with a greater variety of social actors. However, we also recorded a delay in activating some groups, especially of persons affected and in remote areas, as the gathering was not permitted for long periods.

Many of those groups had limited internet connection. More phone contacts and indirect support were attempted in different countries, but this could not fully substitute for face-to-face and group meetings.

Naturally, improving the socio-economic participation of those affected by leprosy is an important part of our Zero Exclusion initiatives. We consider equal participation in society as a basic human right.

One way we gauge this by monitoring how many persons affected by leprosy were able to access loans, agricultural inputs, or (for leprosy affected children) able to attend school, as this will enhance their socioeconomic situation.

Zero Transmission



15,177

Newly detected leprosy cases in NLR intervention areas



672 children

Among those new leprosy cases



239,557

Contacts received SDR-PEP in 283 areas



4,862

Health staff trained on leprosy



Zero Disability



1,814

Health staff trained on prevention of disabilities due to leprosy



Zero Exclusion



894

Local actors better voicing concerns and needs of persons affected



5,263

Health staff sensitised on stigma



3,130

Persons affected with improved socio-economic situation



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 online portal for information on leprosy and leprosy related subjects. The portal offers access to information on key topics, practical tools, and over 30,700 research publications. In 2021 [Infolep](#) attracted 29,500 unique visitors across 202 countries. In addition, [InfoNTD](#) is a portal for sharing information, publications and tools on intersecting issues around neglected tropical diseases (NTDs). Attracting 38,500 unique visitors across 200 countries in 2021, the portal offers access to over 5,500 publications, most of which are open access.

Infolep and InfoNTD aim to enable capacity strengthening for (health) professionals in the leprosy and NTD sector by making knowledge easily accessible. In 2021 both portals began implementation of a three-year roadmap that shares a strategic and structured approach to operating and further developing the portals. This led to the improvement of several services and the start of new

collaborations that contribute to Zero Leprosy and cross-learning on NTDs. NLR supports the mission of both portals, by managing and housing the Infolep and InfoNTD team and by financially contributing to both portals.

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 2021 a total of 21 ongoing and six new research projects received funding support.

The sixth annual LRI Spring Meeting was organised as a virtual event. This also made it possible to open registration to external participants – people with a keen interest in leprosy research, but who would not otherwise have been invited. This resulted in a significant increase in the number of participants with 222 participants from 33 different countries. In addition, in 2021 the LRI Technical Officer continued to support the Global Partnership for Zero Leprosy in the implementation of the research agenda.

World Health Organization (WHO)

From March 2020 until March 2021, Wim van Brakel (Medical Director, NLR) was asked to chair the WHO Task Force on Criteria for Elimination of Leprosy

(TFCEL). The TFCEL prepared criteria with indicators, milestones and targets for leprosy programmes as they move towards the 2030 goal of interruption of transmission and, eventually, elimination of leprosy. Wim van Brakel also assisted the WHO Global Leprosy Programme in drafting technical guidance on this topic and further developing the accompanying tools. This has led to three new tools: the Leprosy Elimination Monitoring Tool, the Leprosy Programme and Transmission Assessment, and the Leprosy Elimination Dossier. The technical guidance document along with the tools will be published in 2022.

Global Partnership for Zero Leprosy (GPZL)

The [Global Partnership for Zero Leprosy \(GPZL\)](#) is a coalition of organizations and individuals committed to ending leprosy. NLR is represented in the Leadership Team and takes part in GPZL-coordinated activities such as Country Reviews to support the development of Country Roadmaps towards Zero Leprosy. LRI's Technical Officer was seconded to the Global Partnership to work on the implementation of the research agenda by setting up working groups to focus on research proposals. Because of the wide representation of stakeholders, GPZL plays an important role in lobbying for the strengthening of leprosy programmes through innovations and increased resources.





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 staff had a leading role in ILEP, with the NLR Medical Director as Chair of the ILEP Technical Commission (ITC) and the NLR CEO as part of the ILEP CEO group. The ITC has set up working groups to focus on practical tools and guidelines that have been identified as important through a wide stakeholder assessment. Several other senior NLR staff are liaising closely with ILEP colleagues in other leprosy organisations regarding programmes, fundraising and communications. NLR has shared its expertise by supporting other ILEP partners on request in the development of joint proposals, providing specific technical support and supporting or facilitating training. The collaboration of ILEP partners increases the effectiveness working on our joint mission towards a world without leprosy.

Dutch Coalition for Disability in Development (DCDD)

NLR's Head of Fundraising and Communication is a board member of 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 people with disabilities, including those affected by leprosy.

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

COR-NTD is a community of researchers, programme implementers and country partners with the shared goal of optimizing NTD control and elimination. COR-NTD works as a programme of the Task Force for Global Health administering research funding from the Bill and Melinda Gates Foundation, USAID and UK Aid for research on NTDs. Leprosy is one of the NTDs, as defined by the World Health Organization. NLR has received funds from COR-NTD for two multi-NTD projects: one in Mozambique and one in India. The implementation of these projects was delayed due to COVID-19 but was continued in 2021. In the online annual COR-NTD meeting, NLR had an active role in presenting research results and practical tools for the assessment of the perception regarding leprosy and the treatment of mental health issues in the Innovation Lab. COR-NTD supports NLR in its ambitions to find innovative ways to reach our end goal.

The NTD NGO Network (NNN)

The NTD NGO Network is a global forum for NGOs to contribute to the global control, elimination, and management of consequences of NTDs as outlined in the internationally agreed World Health Organisation NTD Road map 2021-30. Several NLR staff have been participating in cross-cutting groups of the NNN which comprises more than 80 organisations around the

world. NLR's Medical Director was the chair of the DMDI (Disease Management, Disability and Inclusion) cross-cutting group and he was involved as a member of the NNN Executive Committee until September 2021. Several other NLR staff participate in one of the DMDI working groups. NLR is also well represented in the Skin NTD Cross-cutting Group.

Erasmus MC

NLR has a long history of research collaboration with the Erasmus University Medical Centre (Erasmus MC). This has included major international studies such as the prevention of leprosy (COLEP study), a trial on treatment of early nerve damage in leprosy (TENLEP study), and the LPEP project that examined the feasibility and acceptability of implementation SDR-PEP in eight countries. The ongoing collaboration includes the Stop the Transmission of Leprosy! project and PEP4LEP trial, as well as projects on modelling of leprosy incidence and mapping of leprosy patients, and the development of the NLR SkinApp. Six NLR staff have been working on their PhD in 2021 through Erasmus MC, as well as two staff from partners in PEP4LEP.

Highlights



1.

Support for tens of thousands of persons affected by leprosy

To deal with COVID-19, NLR continued providing emergency aid to help persons affected by leprosy by distributing self-care and medication packages. We started projects that would preventively treat people against leprosy. Healthcare workers have received training in leprosy, the prevention of disabilities due to leprosy, and how to reduce stigma towards persons affected. This allowed us to make a positive impact in the lives of people who have experienced leprosy. [Please watch the video!](#)

2.

New NLR study shows elimination of leprosy is on the horizon

New research by NLR and Erasmus University MC published in PLOS Neglected Tropical Diseases shows that the cumulative number of individuals requiring preventive treatment is projected to be 40 million globally, reducing the incidence by 90% in 22 years. The time needed to reach a 90% reduction in new cases could be shortened if more effective strategies for early diagnosis are implemented, such as extending the number of contacts provided with SDR-PEP, a second dose of treatment after 2 years, or the use of a diagnostic test to identify early infection.

3.

Stop the Transmission of Leprosy! project expands to Nepal and Bangladesh

Due to the impact of COVID-19 and previous delays in study authorisations, the Stop the Transmission of Leprosy! (PEP++) project is expanded to Nepal and Bangladesh since the fourth quarter of 2021. By working in additional study areas, the teams will be able to collect the data necessary from enough participants (around 800,000) to establish the effectiveness of an enhanced treatment that can prevent the disease.

4.

Increase in individual donors and donations in the Netherlands

In the Netherlands, the individual donor base grew from around 44,000 to over 45,000 relations. 2021 was a particularly good year for individual fundraising. The income from individual donors is €4.7 million which is €0.5 million above the expected amount of income. We are extremely proud and honoured to have such loyal donors. This achievement showcases our efforts to maintain a strong connection between our supporters and our goal of a world without leprosy.



5.

Fashion show of jewellery made by persons affected in Brazil

Biojewels made of natural materials produced by artisans from NHR Brazil's Socioeconomic Rehabilitation project were the main attraction at a fashion show. A team of models volunteered to showcase the jewels, including health workers in Rondônia, people representing the Brazilian Ministry of Health, NHR Brazil, and professionals from many areas that work at municipal, state and national level.

The event was attended by Miss Universe Rondônia 2021, Thaise Dias, Miss Teen Rondônia 2020, Letícia Vitória, Mister Rondônia CNB 2021, and Naraiel Ferrari. Their participation was articulated by MORHAN, a social movement of persons affected by leprosy in Brazil

6.

Transition into an Alliance of national NGO's

In 2021 the NLR took important steps in the development of the Alliance. NLR Nepal finalised its transition phase and is now, as per 1 January 2022, a national NGO with its own board and registration independent from NLR in the Netherlands.

NLR Indonesia and NLR India are currently going through the same final transition phase in which they are closely cooperating with NLR in the Netherlands every step of the way. NLR Indonesia and NLR India expect to end their transition phase and start their life as autonomous national NGOs during 2022. NLR CEO Linda Hummel visited Nepal to formalize the transition.



7.

Ready4PEP kick off in Nigeria and Mozambique

In July 2021 LTR Nigeria kicked off community activities in Nigeria with an official launch. Immediately afterwards all six states got off to a quick start with contact tracing of former leprosy patients and SDR-PEP administration. Many new leprosy cases were identified during the screening of close contacts. This confirmed the importance of the interventions and success of the strategies used to find and screen contacts. Nigeria is one of the first countries to implement SDR-PEP on a larger scale. A total of 21,000 contacts are expected to receive SDR-PEP.

In Mozambique official authorisation delayed the start of SDR-PEP administration in the districts. However, towards the end of the year the first SDR-PEP was administered to contacts of leprosy patients in the Rapale district in Nampula.

8.

PEP4LEP kick off in Mozambique

In September 2021 NLR organized the launch of the PEP4LEP research project to implement leprosy prevention methods in the Mogovolas district of Nampula province, Mozambique.

The Provincial Governor's representative and the PEP4LEP implementing parties – NLR, Lúrio University and the Ministry of Health – witnessed the first hand out of what for Mozambique was new preventive medicine for contacts of leprosy patients. The project is funded by the European & Developing Countries Clinical Trials Partnership (EDCTP), supported by the European Union and by the Leprosy Research Initiative.



9.

Technical Capacity Building in Action!

NLR is known for its leprosy expertise and its extensive experience in the leprosy field. To ensure this is maintained it is important to invest in recruitment, retention and capacity strengthening of NLR technical staff. The Technical Capacity Building in Action! is aiming to strongly contribute to making NLR future proof in terms of technical expertise.

The project officially started in March 2021 with the establishment of an Alliance wide project team and a successful online Master Class on the transmission of leprosy attended by more than 125 colleagues.

TCB IN ACTION!

10.

Increase in number of contacts that received SDR-PEP

In NLR's intervention areas a total of 239,557 close contacts of persons affected by leprosy received the preventive treatment for leprosy: SDR-PEP. Even though this is lower than our target due to COVID-19 restrictions, it is four times higher than in 2020. The number of regions where SDR-PEP is implemented also increased from 158 to 283 areas.



Our Organisation





Achieving Zero Leprosy requires a solid, goal-oriented organisation that allows flexibility to change when necessary. We were able to support and stay connected with persons affected by leprosy during the second year of the pandemic. This was made possible through the dedication and hard work of our office and field staff, NLR's Supervisory Board, donors, volunteers and partners. We are very proud of their resilience, expertise and perseverance. In most countries we worked mainly from home. This was another year in which we achieved results and kept our eyes on the goal of a world free from leprosy and its consequences.

Staff Composition

NLR's international office is based in Amsterdam, the Netherlands, where at the end of 2021 our staff comprised 43 employees (38.3 FTE) and 100 volunteers. In 2021 the management and implementation of field activities was delegated to five professional country offices located in Mozambique (16 employees), India (78 employees), Indonesia (58 employees), Nepal (49 employees) and Brazil (36 employees). Together, these country offices employ a total of 232 people.

Sickness absence rate

In 2021 the national average absence rate in the Netherlands was 4.8%. NLR's target maximum is set at 4.1%. The overall absence rate in 2021 was 9%, a decrease compared to 11% in 2020. Five employees dealt with long-term sickness due to various reasons, which accounts for more than 90% of the total sickness absence. This high rate of long-term sickness absence has been monitored closely by HR and management and steps have been taken in 2021 to counter this type of absence. This close monitoring will continue in 2022.

Working place and conditions

COVID-19 has shown us that the possibilities of working from home are much more extensive than we had assumed in previous years. In 2021 a new COVID-19 working from home agreement was established, covering issues related to COVID-19 and working from home. This agreement is linked to the government measures and has been in effect for all of 2021. With the outlook on the situation changing in the future, a project group was set up to research possibilities and wishes for the future of our office use and layout. The outcome was a proposal for hybrid working, 50% from home and 50% in the office. An adjusted working from home agreement was established for 2022 that accommodates the future hybrid situation but has yet to be implemented.

“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 in the international office is a great asset for NLR in several ways. The Employee Representative Body (PVT) 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.

Through the PVT employees can influence decisions that are important to them, providing input to the CEO on plans and insights from across the organisation. In 2021 the body included four new members. The main points of attention included: (1) new or updated job profiles for all staff members, (2) long-term sickness absence, (3) office redesign, (4) the impact of COVID-19 on our staff and ways of (remote) working, and lastly, (5) the organisational transition. The PVT gave positive advice on the new working from home agreement. Valuable unsolicited advice was given on NLR's contract policy that led to better information provided to job applicants. Two staff meetings were organised to discuss relevant HR and business-related topics between staff and the Employee Representative Body. The Employee Representatives Body met with the Chair of the Supervisory Board in September.

Risk analysis and control

NLR's 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, monitoring initiatives are identified and put in place.

To monitor our operations, we have systems in place to oversee both our financial progress as well as the progress of our leprosy projects. This ensures that our spending is in line with our strategy and accountability principles. In 2021 four quarterly financial reports were produced which were discussed by management as well as NLR's Financial Audit Committee and shared with the Supervisory Board. In addition to this we updated the (Alliance-wide) risk inventory as part of our 2022 Annual Plan preparations. This inventory has been discussed by the Management Team and was shared with our Financial Audit Committee and Supervisory board in their first 2022 meetings.

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 warning, minimize the chance of their occurrence and, where possible, their impact. The Financial Audit Committee of the Supervisory Board expressed confidence that NLR has sufficient influence over the risks identified.

Quality system (ISO)

In October 2020 NLR extended the ISO 9001:2015 and the branch-specific ISO 9001:2015 Partos certifications for a further three years. We received the recertification in 2021. The audit highlighted several opportunities for improvement and these will be addressed in 2022.



General Data Protection Regulation (GDPR)

Adhering to the General Data Protection Regulation is part of our day-to-day operations and a key focus 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 in place were continued and consolidated in 2021. 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. One security incident regarding the compliance with the General Data Protection Regulation was reported but had no serious consequences for those involved.

The Netherlands Fundraising Regulator (CBF)

When a charity has been recognized as such by the CBF, you can trust that the organization has been closely reviewed. In 2021, NLR supplied data for the Annual Check and Reflection of the CBF. In their Interim Test

they checked whether there are circumstances or events that require NLR to take action to continue to meet the standards. No deviations from the standards of the accreditation scheme have been established. Our recognition will be continued.

IT and office investments

For IT our general focus has been on security. New measures were taken to make sure our systems and data are protected. In 2020 we implemented our new donor Customer Relationship Management (CRM) database which we enhanced and further developed in 2021.

A lot of work was carried out on a new Grant and Programme Management system that was delivered in 2021. It contains data of all our worldwide projects for which the 2021 data was entered in the system. Full utilisation of the system is ongoing.

Some minor investments have been carried out in order to keep our equipment up-to-date. A plan for returning to the office after the pandemic has been developed for IT and will be applied in 2022.

Corporate Social Responsibility

NLR operates on a carbon-neutral basis. As in previous years, in 2021 our CO2 emissions from air travel, office heating and printing were compensated by contributions to sustainable energy projects. Naturally, our carbon emission was still significantly lower than before COVID-19 as staff still worked mostly from home and air travel only took place once in the entire year. Total emissions in 2021 amounted to 36 tons of CO2, a decrease compared to 71 tons in 2020. The expectation is that, even post-COVID-19, travelling will take place less than pre-COVID-19 due to the possibilities for virtual meetings and in order to lower our carbon footprint.

In accordance with the Financial Management of Fundraising Institutions guidelines issued by Goede Doelen Nederland (the Dutch branch organisation for charities), the 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

We work with vulnerable groups of people who must be treated with respect and dignity. Our donors entrust us with financial resources and expect our staff and partners to spend these responsibly and act with integrity. We have quality standards for the integrity policy framework for all NLR Alliance members. These standards cover the following:

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

Alliance members have implemented the policy framework in their organisations. The reporting system seems to work as the integrity officer received three complaints relating to one of the branch offices in 2021.

NLR's efforts relating to transparency on integrity resulted in recognition from Goede Doelen Nederland (the Dutch branch organisation for charities) who highlighted our activities in this area as 'best practice' during an event focusing on integrity.

Issues report

In 2021 the confidential advisor for the Amsterdam office received three reports about negative cooperation between employees and their managers. In one of our branch offices three cases relating to leadership style were reported to the CEO and to the integrity officer of NLR Amsterdam. The CEO and Head of Programmes have discussed these cases anonymously with the Country Director and local board of the branch office concerned. Measures were taken and management training was conducted. The situation is monitored and recommendations for further improvement have been made.

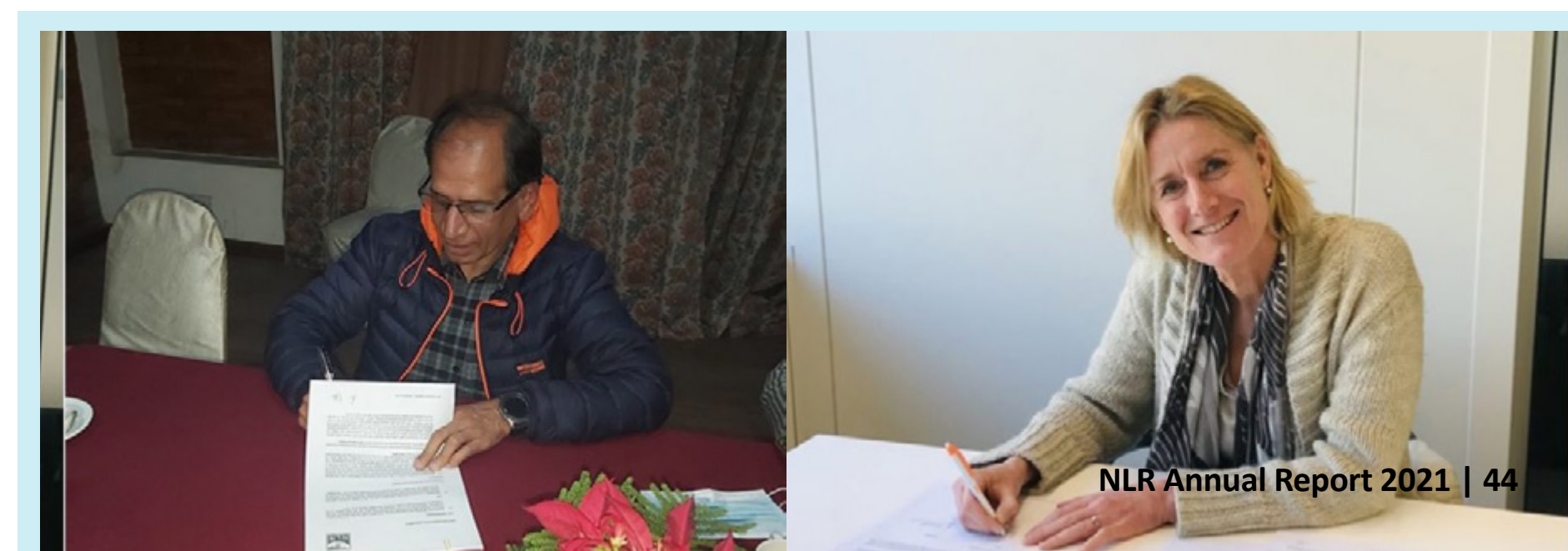
Progress on Alliance development

December 2021 saw an exciting and memorable moment in the history of NLR: NLR Nepal completed the transition process in full and signed the first collaboration agreement with NLR in our Alliance.

As of 1 January 2022, NLR Nepal is the first national NGO to perform all its activities as a national NGO with its own board and registration independent from NLR in the Netherlands.

As the chair of the board of NLR Nepal, Mr Prakash Wagle said, *"We are independent, but at the same time I would like to think of the NLR Alliance as interdependent NGOs working together towards the same goal. After the thorough preparations in the five years behind us, this is a great step for all of us and I am very happy to be part of it!"*

NLR Indonesia and NLR India are currently going through the same final audit phase in which they are closely cooperating with the NLR international office. NLR Indonesia and NLR India expect to complete their transition phase and move forward as autonomous national NGOs during the course of 2022.



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 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 two female members and four male members until mid-March 2021, and three males and three females for the remainder of the year.

In 2021 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) until March 2021.

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
- 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.
- Member of the Board, Vrienden van Abrona

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.
- Member of the International Union Against TB and Lung Disease.

Mrs N. Tromp

First term, until 18 June 2025.

- Health systems advisor, KIT Royal Tropical Institute
- Member of The Netherlands Society for Tropical Medicine and International Health.



Main activities and decisions of the Supervisory Board

The Financial Audit Committee met four times to discuss a variety of finance-related issues in preparation for 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 process were also discussed.

The 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 staff and Board.

In 2021 the Supervisory Board addressed the following:

- Progress 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 also informed about global leprosy case data and challenges presented by COVID-19.

Further activities and decisions included:

- The progress of the transition process was discussed during every meeting. In March the audit process was approved and in September and December special attention was paid to the transition of NLR Nepal to an independent national NGO after the successful completion of a pre- and final audit.
- In June the Board approved the 2020 Annual report and Annual accounts of LRI, and in September the 2019 Annual Report and Annual Accounts of NLR.
- In June Noor Tromp started in the Supervisory Board as the successor to Paul Klatser
- In November an extra Supervisory Board Meeting was held to discuss the pre-audit reports of India and Indonesia. For both country offices this resulted in findings and recommendations to be followed up before the final audit phase planned for 2022.
- At its December meeting the Board approved the 2021 Annual Plans and Budgets of NLR and the LRI. Following a selection process, Vincent van Slingerland was appointed as the successor to Redmer Greveling, starting in 2022.

In December 2021 the Supervisory Board carried out a self-evaluation. In general, the Board is satisfied with the way it operates and continues to strive for a better balance in meetings between receiving information, discussion and decision making.

Unfortunately, due to COVID-19 measures the annual visit to the international office and meetings with NLR's staff were cancelled in 2021. For the same reason Supervisory Board members were unable to visit leprosy projects.



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 Goede Doelen Nederland. 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. Every three years the Supervisory Board reviews the remuneration of the CEO, with the most recent review having taken place in 2020. The Regulation uses three criteria to define the maximum standards for annual incomes: size, complexity and organisational context; leading to a total BSD score of 465 points.

For 2021 this amounted to a maximum average annual income of €141,765 (€141,273 in 2020). The annual salary of Linda Hummel in 2021 was €137,767 (€137,767 for Jan van Berkel in 2020). The combined total of annual income, taxable allowances/additions, pension charges and pension compensation and other (future) rewards, amounted to €145,927, which remains below the maximum allowed in the regulations of €209,000 per year for 2021 (this maximum was €201,000 in 2020).

Name	L. Hummel	J. Van Berkel
Function	CEO	CEO

Employment	2021	2020
Duration contract	Indefinite	Indefinite
Hours/week	40	40
Part-time percentage	100	100
Period	1/1-31/12	1/1-31/12

Remuneration in EUR	2021	2021
Annual Income		
Gross wages/ salary	107,220	123,818
Holiday allowance	9,478	8,997
End-of-year payment	4,289	4,953
Variable annual income	-	-
Total reward	120,987	137,767
Social security charges (employer's contribution)	9,474	7,243
Pension charges (employer's contribution)	15,106	8,180
Other remuneration	360	1,816
Total other charges and compensations	24,940	17,240

Total remuneration	145,927	155,007
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Organisational Perspective

Looking forward

A new phase in the COVID-19 pandemic leaves more room to think beyond day-to-day struggles. There is a lot of catching up to do, primarily in field work. Backlogs that were created by the crisis push us to focus even more on new case detection.

However, crises can create innovation. In the coming year(s) new research insights and technological options (virtual meetings, social media for field work, geographic information system mapping of close contacts, etc.) support the acceleration we need on our road towards zero leprosy in the most cost-effective way.

We can identify some positive trends. We see more cooperation between relevant NTD organisations, those specializing in skin in particular. When the situation allows, renewed efforts can further strengthen common ground through lobby and policy influencing strategies. We see the benefits of this in the networks in which we actively participate. Nevertheless, the leprosy sector is a small ecosystem and it is therefore essential to keep the door to other relevant sectors open for information and inspiration.

We foresee a continuing battle for attention when it comes to leprosy elimination within health systems. It is therefore best to integrate control activities of various diseases (e.g. NTDs, including leprosy) into national health programmes. This is more effective than standalone leprosy projects, but it means opening new doors for lobbying to increase attention for and investment in leprosy control. As influencing policy becomes a more crucial part of our work it will be incorporated into our next Multi Annual Strategy.

Counteracting diminishing knowledge of and expertise around leprosy at various levels is a constant focus of our attention. Inspiring a potential young workforce is therefore very much on the agenda. We must maintain existing knowledge in our current networks and see where we can amplify efforts to generate appeal for work in the leprosy field. We do this by involving PhD candidates, but also through recruiting students and younger generations who understand tradition, while at the same time have a natural tendency to positively disrupt, challenge and change.

Our transition into an Alliance of national NGOs paves the way to more national ownership and leadership. This shift of power best serves persons affected by leprosy as each office is more capable of allocating resources to fit their strategic goals and local contexts and needs. Fighting leprosy is an endgame. With our Three Zero Strategy we keep moving forward, goal oriented and motivated, until No Leprosy Remains

Finances

Result 2021 in short

The annual accounts are a consolidation of the annual accounts of both NLR and the Leprosy Research Initiative (LRI). The total consolidated income in 2021 was €9.6 million (2020: €10.4), while €10.0 was budgeted. Total expenses were €11.2 million (2020: €11.2), while €13.8 million was budgeted.

After adding the positive result of our financial investments (€0.9 million), the overall negative result for 2021 is €0.7 million (2020: €0.4 million negative result), which was subtracted from our earmarked reserves and funds. We budgeted a negative result of €3.6 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

2021: income

Overall income

Total income in 2021 was below budget and lower than last year. Income from individual donors was higher than budgeted and higher than in 2020, when income from legacies was significantly lower than last year. Once again, we were happy to receive our annual contribution of €1.35 million as a beneficiary of the Dutch Postcode Lottery. Our income from other non-profit organisations totalled €2.4 million. This was higher than last year, but lower than budget because institutional donor income expected for 2021 moved to the next year due to delays in the execution of projects. We gained €0.9 million in positive results from our financial investments.

Fundraising in the Netherlands

In the 2021 budget we anticipated income from our own fundraising (excluding income from legacies) to increase to €2.6 million. Actual income amounted to €3.0 million, which was the direct result of an additional investment made in our successful door-to-door campaign. As a result of this campaign the number of committed donors continued to grow in 2021, thereby strengthening the structural income in the years to come.

Legacies

After a thorough analysis of our year-by-year income from legacies, we budgeted our 2021 income from legacies at €1.6 million. In 2021 we received €1.9 million. The number as well as the average size of individual legacies were lower than we received in 2020, when the total amounted to €3.6 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 2021 we recognised €63,000 as income, covering expenditure for our planned activities.

European and Developing Countries Clinical Trial Partnership (EDCTP)

In 2018 a total of almost €3.2 million was awarded by the EDCTP for the PEP4LEP project. This multi-partner project will be implemented over a period of 52 months from 1 October 2018. In 2021 around €536.000 was recognized as income from this grant.



Financial Highlights

2021: expenses

Overall expenditure

Total expenditure in 2021 was behind budget yet similar to last year, which was again the direct result of the COVID-19 pandemic affecting our work. In 2021 we spent €9.2 million on our objectives, which was 82% of our total expenditure (2020: 81%).

International leprosy programmes

In order to fulfil our mission, we have operations in nine leprosy endemic countries as well as in the Netherlands. Despite our work being made more difficult by COVID-19, we were able to spend €7.7 million on international leprosy programmes, which was lower than budget at €9.5 million and similar to previous year.

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 2021 €0.9 million was spent on research projects and running costs. Total expenditure was almost 55% lower than budgeted due to the impact of the COVID-19 pandemic. This was only slightly higher than the €0.8 million expenditure of 2020.

Fundraising

Expenditure on fundraising was €1.6 million, where we initially budgeted €1.3 million. We invested in attracting more committed donors in order to secure future growth in fundraising income that will enable expansion of our leprosy programmes in endemic countries. We continued our door-to-door donor recruitment with positive results.

Total spending on our own fundraising in relation to total income raised amounted to 16% (2020: 15%).

Financial income and expenditure

The balance of financial income and expenses regarding invested reserves was €0.9 million in total. This was a very substantial increase against budget (€0.2 million) and more than last year (€0.4 million). Yield on the portfolio was 8%.

Expenses from our earmarked reserves

We spent a total of €1.1 million from earmarked reserves: €0.1 million on transforming our branch offices into local NGOs that are embedded in their local contexts; €0.1 million on investments in our IT-operations; €0.4 million on investments in our fundraising; €0.2 million on projects in leprosy endemic countries and €0.1 million in medical technical capacity building.

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'. The funds that remained unspent at the end of 2017 were placed in 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 2021 activities were planned for a total budget of €1.7 million. In 2021 a total of €1.4 million was spent, compared to €1.6 million in 2020. Earmarked funds at end of 2021 amount to €3.6 million, which are due to be spent in 2022 and beyond.





Special Notes

Consolidated annual accounts

The Leprosy Research Initiative (LRI) was registered as a foundation under Dutch law in 1 June 2015. The LRI represents a unique model of cooperation and coordination in the funding of leprosy research. Members of LRI include: American Leprosy Missions (ALM), German Leprosy Relief Association (GLRA), The Leprosy Mission International (TLMi), Damien Foundation, Anesvad Foundation and NLR. 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. NLR manages LRI operations, implementing the decisions of the LRI Executives Group, overseen by the NLR Supervisory Board. The LRI and NLR 2021 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 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 Dutch Charities Branch Organisation (Goede Doelen Nederland), 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 Supervisory Board for specific purposes to spend in 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 the portfolio 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 2021

For 2022 we aim to increase our income further by focussing on both individual and institutional donors. The total budgeted income for 2022 is €10.2 million.

To finance our ambitious plans for 2022 we are budgeting a total expenditure of €14.5 million. This will allow us to invest further in both our expenditure on objectives as well as strengthening our fundraising and organisational structure. From this total expenditure €3.9 million is budgeted to be spent from earmarked reserves and funds.

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

NLR Budget 2022

This is the approved consolidated NLR 2022 budget. For the separate 2022 LRI budget, please refer to LRI's [annual accounts](#) of 2021.

Income	€
Income from individuals	4.455.086
Grants from governments	758.971
Income from other non-profit organisations	3.223.865
Income from companies	-
Income from lotteries	1.350.000
Income from allied and joint non-profit organisations	-
Income from sales of products and services	14.000
Other income	349.000
Total income	10.150.921

Expenses		€
International Leprosy programmes	9.422.887	
Information and awareness raising	358.604	
Scientific and operational leprosy research	2.312.000	
Spending on objectives	12.093.481	
Fundraising expenses	1.943.584	
Management and administration	420.327	
Total expenditure	14.457.392	
Balance of income and expenditure	-4.306.470	
Financial Income and Expenses	400.000	
Balance of income and expenses	-3.906.470	
Destination of the balance of income and expenses		
Additional / Withdrawal from		
Continuity reserve	-	
Earmarked reserves	-2.241.470	
Earmarked funds	-1.665.000	
Total mutation of reserves and funds	-3.906.470	

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