Getting closer to our dreams
GETTING CLOSER TO OUR DREAMS

WE WORK TOWARDS A WORLD FREE OF LEPROSY AND EXCLUSION DUE TO DISABILITIES.

TARGET 2030:
NEW LEPROSY CASES DECREASED BY 90%
A HISTORICAL YEAR

2017 truly has been a historical year for the Netherlands Leprosy Relief (NLR). We celebrated our fiftieth anniversary, commemorating the inception of our organisation by our ideals-driven founders Dick Leiker and Ciska Anten on 30 March 1967. But what exactly were we celebrating? Leiker and Anten had a joint dream of seeing a world without leprosy. Now, half a century later, we have yet to achieve that goal.

Nevertheless, there is so much we have achieved as an organisation that we can be truly proud of. Back in the 1960s, there were around fifteen million new leprosy cases; today that figure stands at just over 200,000 annually. Although that number has hovered around the same level for some years now, when we look back and see how far we have come, it really is incredible. But we also recognise that the graph has become horizontal, what we need now is a concerted push to bring leprosy down to zero.

That momentum has been brought to life thanks to the Dutch Postcode Lottery (NPL). From their “Dream Fund,” we were given more than nine million euros for our breakthrough project to prove it is possible to stop the transmission of leprosy. We believe this will be a real game-changer. In this five-year project, we will be running a screening test to detect leprosy in its early stage (no noticeable symptoms) with people who have had direct contact with new cases of leprosy. Those who test positive are given an enhanced preventative treatment called PEP++. Other contacts will receive a single dose of rifampicin (SDR) to also reduce their risk of developing leprosy.

One of the most challenging aspects of dealing with leprosy is the long incubation period; untreated patients can unknowingly infect others for years. We believe that by taking this front-foot, aggressive approach, we can get one step ahead of the disease.

As we celebrated our fiftieth anniversary as an organisation, we have fixed our focus on aiming for a leprosy-free world long before NLR reaches its centennial anniversary! Together with your support behind us, we are edging closer to that goal every single day.

Leprosy is not only a disease with massive physical consequences, but also one that sadly causes social exclusion from society. People are left feeling that they have lost their humanity. In our work, we come alongside those who are affected by leprosy and a huge part of our role is to tell their stories to a wide audience. How has our work significantly changed their lives? What are their dreams for the future?

It goes without saying that we cannot do our work without the loyal support we receive from many people and organisations. We are constantly grateful for the help and commitment of so many.

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A joint dream of seeing a world without leprosy

Bram van Ojik
Chair, Supervisory Board

Jan van Berkel
Director
In 2017, the Netherlands Leprosy Relief (NLR) has been actively working in Mozambique, India, Indonesia, Nepal, and Brazil. We have started the process of phasing out our work in Nigeria and the Mekong Region.

All of our programmes are aimed at promoting and supporting health, ability, and full inclusion in society for persons affected by leprosy or living with disabilities.

To achieve this, we focus on four key priorities:

1. **Stop transmission of leprosy**
2. **Combined approaches to prevention and management of disability**
3. **Disability-inclusive development**
4. **Reduction of stigma and discrimination**

These priorities are in line with:

- **The Global Leprosy Strategy**
  “Accelerating towards a leprosy-free world”
  Of the World Health Organization (WHO)

- **Triple Zero campaign**
  Of the International Federation of Anti-Leprosy Associations (ILEP)

They also contribute towards achieving:

- **The Sustainable Development Goals (SDGs)**
  90% reduction of leprosy cases by the year 2030
  Of the United Nations (UN)
What have we achieved worldwide?

- **60,041 new leprosy cases** were found, diagnosed and treated in our programme areas.
- **28,390** direct contacts of new leprosy patients were given a single dose of rifampicin (SDR) to reduce the risk of developing leprosy by 50-60%.
- **3,116** health workers, community volunteers, accredited social health activists (ASHAs), and government health staff were trained on leprosy.
- **8,023** people were informed and educated on leprosy to raise awareness.
- **10,891** people from communities were informed and educated about general disabilities to raise awareness.
- **792** existing self-care groups (formed before 2017) and **50** newly formed self-care groups were supported.
- **1,244** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability.
- **6,590** people's lives were changed with reconstructive surgery.
- **101** Disabled People’s Organisations (DPOs) received assistance to promote participation of people with leprosy-related disabilities.
- **5,162** persons with disabilities were oriented on their rights so that they can claim them.
- **547** people received a microcredit to help them become self-employed.
- **463** people received vocational training to learn a trade.
- **2,273** children of leprosy-affected persons received financial support for their education.
- **1,244** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability.
- **14,066** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
- **1,244** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability.
- **869** people were provided with leadership training.
How do we spend our money?

Over the past year, we received a total income of €20.9 million, including €9.38 million from the Dutch Postcode Lottery (NPL) through its “Dream Fund”. This continued support is vital as it enables us to continue our fight to beat leprosy and change the lives of those affected. Throughout the Netherlands, we received backing from 45,660 donors, 350 volunteers, and many dedicated supporters who have taken part in different fundraising activities. In addition to this, we also received additional funding from governments, global organisations, and fifteen institutional partners.

TOTAL INCOME IN 2017: €20,884,000

TOTAL EXPENSES IN 2017: €11,260,000

EXPENSES ON THE OBJECTIVES: €10,076,000

% of total income: 48.2%  
% of total expenses: 89.5%

OWN FUNDRAISING COSTS

Income from own fundraising: €5,918,000

Expenses on own fundraising: €679,000

% of income from own fundraising: 11.5%

Average for the years 2015-2017: 16.2%

EXPENSES ON MANAGEMENT AND ADMINISTRATION: €505,000

% of total expenses: 4.5%

This is well under the maximum of 25% set by the Dutch Central Bureau for Fundraising

Expenses on costs of fundraising of income own fundraising: 11.5%

Expenses on management and administration: 4.5%

Other details concerning our income and expenses are shown in the Annual Accounts.
Our five-year project “Stop the Transmission of Leprosy!” was recognised by the Dutch Postcode Lottery for support through its “Dream Fund.” Intensive preparations for the implementation of the project – in India, Indonesia, and Brazil – took place throughout the year.

Belinha, a Mozambican woman with lymphatic filariasis, joined our combined self-care group in her village. She invited her neighbour Fatima to join the group after seeing a skin patch. The diagnosis of leprosy was confirmed and Fatima received treatment. By looking after herself and her fellow villagers, Belinha assisted in tackling two diseases at the same time.

The model of the Disability-Friendly Communities in Nepal was positively evaluated and will serve as a template for our work on disability-inclusive development worldwide.

The Ministries of Health of India and Nepal incorporated the Leprosy Post-Exposure Prophylaxis (LPEP) approach into their National Leprosy Programmes. This ensures sustainability of this innovative intervention.

Our SkinApp for peripheral health workers was the third-place award winner for The Spindle Best Idea 2017 at the Partos Innovation Festival. We made the app available for download in the Google Play Store and the App Store and started a field test in three provinces in Mozambique.

We celebrated our 50th anniversary.
OUR VISION MISSION & STRATEGY

VISION
A world free of leprosy and exclusion due to disabilities.

MISSION
The Netherlands Leprosy Relief promotes and supports health, ability, and full inclusion in society for persons affected by leprosy or living with disabilities.

STRATEGY
The Netherlands Leprosy Relief works towards its goals by:

- Working with governments, non-governmental organisations (NGOs), research institutions, and Disabled People’s Organisations (DPOs) promoting access and quality of services through training, expert advice, research, and innovation.

- Strengthening capacity through training, expert advice, research, and innovation.

- Developing policies and programmes that are in accordance with the Sustainable Development Goals (SDGs) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD), aiming 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 persons with disabilities.

- Integrating leprosy work with other neglected tropical diseases (NTDs) and disability work.

- Lobbying to keep leprosy and disability inclusion on policy agendas at all levels.

- Facilitating rehabilitation services, reduction of stigma, and the promotion of self-care and empowerment.

Read about our future plans >>
Our Key Priority Programmes (KPPs)

In 2017, we initiated four Key Priority Programmes (KPPs) to give a greater focus and direction to our work. These programmes are in effect in multiple countries, promoting our Country Offices to work closely together. In 2017 we focused on the development of KPP 1 and 3, with KPP 2 and 4 starting in 2018.

These KPPs are in line with the Global Leprosy Strategy (“Accelerating towards a leprosy-free world”) of the World Health Organization (WHO), and the Triple Zero campaign (“Zero Transmission, Zero Disabilities, Zero Discrimination”) of the International Federation of Anti-Leprosy Associations (ILEP). They also contribute towards achieving the Sustainable Development Goals (SDGs) of the United Nations (UN), which targets a 90% reduction of leprosy cases by the year 2030.

KPP1
KPP1: Stop transmission of leprosy

Leprosy can only be eliminated if we can prevent people from getting leprosy and if we can stop the transmission of the leprosy bacilli.

Under KPP1, we continued our part of the Leprosy Post-Exposure Prophylaxis (LPEP) programme. The programme tests the feasibility and acceptability of a single dose of rifampicin (SDR) as a preventative treatment for leprosy. Rifampicin is given to direct contacts of newly diagnosed leprosy patients to decrease their risk of developing the disease. We have implemented the programme in India, Indonesia, and Nepal since 2015, in close collaboration with the Ministries of Health, other ILEP members and Novartis Foundation.

Over the next five years, we will be fully dedicating our efforts to go further than ever before in stopping the transmission of leprosy in an innovative project which is funded by the Dutch Postcode Lottery (NPL) through its “Dream Fund.” In this project, we screen direct contacts of new cases using a screening test that can detect leprosy at a subclinical stage. Those that test positive are given an enhanced prophylactic treatment, which we have named PEP++. Other contacts will receive a single dose of rifampicin (SDR). KPP1 is not only directly making a huge difference in preventing new cases of leprosy, it is also generating scientific evidence with which we can inform and influence governments, the World Health Organization (WHO), and investors to follow this path towards stopping transmission.
Under KPP2 we will use the experience we have with leprosy to integrate with other disease programmes, as we are already doing in Mozambique. In the last three years, we have assisted people living with the effects of leprosy and lymphatic filariasis, a parasitic disease transmitted through the bite of infected mosquitoes. We do this (with funds of UK-based ILEP member Lepra) by providing them with treatment and disability services through combined self-care groups, assistive devices, and reconstructive surgery. It reduces their discomfort and physical burden, which often causes stigma and restricts people’s livelihood opportunities.

As leprosy shares many similar symptoms with other neglected tropical diseases (NTDs) and diseases causing nerve damage (such as diabetes), the physical needs of those affected are similar. We can tackle disabilities more effectively and efficiently by implementing combined approaches.

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Under KPP3, an important mechanism for inclusion is participation in Disabled People’s Organisations (DPOs). We work on and advocate ways to promote participation of people with leprosy-related disabilities in DPOs and to include their needs to make sure they can enjoy all their rights.

In Nepal, we are working on Disability-Friendly Communities; where all relevant stakeholders become responsible and accountable towards fulfilling the rights of persons with disabilities (including those disabled by leprosy) as provisioned in laws, policies, and programmes.

Our disability-inclusive development initiatives aim to ensure that people with disabilities, caused by leprosy and other diseases, can fully and actively participate in society on an equal basis.
KPP 4

Reduction of stigma and discrimination

It is not just the physical effects of leprosy which devastates lives. The prejudice that people experience is separating them from society and excluding them from full participation in all ways of life, causing many of them to feel ashamed and worthless. This terrible stigma is also a barrier to treatment. Many people hide away, avoiding a diagnosis for fear of its consequences. It is very important that we keep fighting this stigma and discrimination.

In each KPP we will give special attention to this.
The year in review

In 2017, our fiftieth anniversary year, fundraising was hugely encouraging, both in private and Institutional Fundraising. We are above budget, in the plus.

We are particularly excited about the decision of the Dutch Postcode Lottery (Dream Fund) to support our work towards the project “Stop the Transmission of Leprosy!” It has massively boosted our potential to work over the next five years on breakthrough innovations in leprosy prevention and decreasing transmission. The implementation began in 2017 and has been a substantial contribution to our Key Priority Programme (KPP) “Stop transmission of leprosy” in India, Brazil, and Indonesia. The approval reaffirmed our ambitions to make innovative contributions in bringing our dream of a world without leprosy ever closer.

The plus in fundraising is connected to the decision in 2016 to reduce our budget due to declining income from legacies. This decline unfortunately forced us to refocus and downsize our operations from eleven countries down to five. In 2017, we started to phase out the funding of our programmes in Nigeria and the Mekong Region. The transition funding will be ending in 2018. At the offices of both countries, our local teams were facilitated to assess opportunities to continue the non-leprosy parts of their programmes. These are externally funded as both offices prepare to register as independent, local NGOs.

In 2017, our programme strategy continued to focus on two major innovation processes: decentralising the organisation in accordance with the NLR 2020 process; and developing Key Priority Programmes (KPPs) to bring a more concise and clear direction to our work.

NLR2020 is the process of transforming our Country Offices into local NGOs that are embedded in their local contexts. We are pleased that throughout 2017 this progressed further. As expected, NLR 2020 did face some challenges, as in most offices a change of leadership coincided with preparing to hand over governance to a new local board.

Our extra efforts to invest in strengthening the capacities of our staff in programme management and Institutional Fundraising continued in 2017. First successes were booked in Institutional Fundraising and delivered through intensive collaboration between Country Offices and our International Office.

The quality of our operational processes and standards were boosted in 2017 by ISO certification of the International Office and the further roll-out of a cloud-based financial administration system called “NAV Vision,” which will be finalised in 2018.

We firmly believe in the utmost importance of a more intensive collaboration among all the key stakeholders in the fight against leprosy. To underline this, we actively participated with the International Federation of Anti-Leprosy Associations (ILEP) in their ongoing efforts to develop the Global Partnership for Zero Leprosy, launching in 2018.

“ITBoosted our potential to work on breakthrough innovations in leprosy prevention and decreasing transmission”
A look ahead

In the past two years, the Netherlands Leprosy Relief has started some big processes of change, such as decentralisation under NLR2020, working with Key Priority Programmes (KPPs), and implementing innovative projects to stop the transmission of leprosy. In 2018 we will continue implementing these significant changes.

Under NLR2020, we are transforming our Country Offices and International Office in the Netherlands into an alliance of five plus one local NGOs who are all well-connected with governments, networks, and organisations of persons affected by leprosy and persons with disabilities in their countries. We are also going to continue to strengthen planning and programme skills. Our local fundraising teams will continue to receive additional training. Our goal is that over time, each office will become more financially independent and self-sustaining. NLR2020 has been underway for more than two years now, therefore we will be holding a mid-term review in 2018 to learn from the progress we have made so far.

In 2018, we will continue to structure our work within the frame of the four KPPs. Under KPP1 (“Stop transmission of leprosy”), we will support the roll-out of Single Dose Rifampicin chemoprophylaxis (SDR), which prevents those who have come into contact with persons affected by leprosy from developing the disease. After intensive preparations throughout 2017, we will start implementing the five-year Dutch Postcode Lottery Dream Fund Project. Under KPP3 (“Disability-inclusive development”) we are building Disability-Friendly Communities, based on learnings from projects in Nepal in the previous years. Projects outlined in KPP2 and KPP4, regarding combined approaches to disability prevention and management and reduction of stigma and discrimination, will be developed in 2018.

In the international arena, we will continue to participate alongside ILEP with the framework of the Triple Zero Campaign. In addition to this, we are also involved in the launching of the Global Partnership for Zero Leprosy in 2018, which will bring together and unite all major stakeholders across the world to develop roadmaps to end leprosy.

With many leprosy experts getting older, we will be investing in a plan to sustain technical leprosy capacity within the organisation. We will be specifically looking into how we can publish evidence that has already been obtained through our programmes but has not yet been published.

In our private fundraising in the Netherlands, we will invest in future-proofing fundraising by changing the previous emphasis on short-term donations towards long-lasting partnerships with private donors.

In 2018, we will be investing in and updating our ICT and communications infrastructure. The focus will be on external communications with donors, other stakeholders, and the public at large, as well as to support an effective platform for web-based working and communicating within NLR.

In 2018 we will continue implementing significant changes
WORKING ON INNOVATIVE BREAKTHROUGHS

Our innovations

The last decade has seen a stagnation in the number of new leprosy cases, levelling off to between 265,000 and 210,000 per year globally. To achieve Sustainable Development Goal (SDG) 3, a 90% reduction in the number of people requiring treatment for neglected tropical diseases (including leprosy), new approaches are urgently needed. We report on four innovations that the Netherlands Leprosy Relief (NLR) is currently working on.

DREAM FUND PROJECT: STOP THE TRANSMISSION OF LEPROSY!

One of the most exciting developments for NLR in 2017 was that the project “Stop the Transmission of Leprosy!” received financial support from the Dutch Postcode Lottery through its “Dream Fund.” This five-year initiative combines research on a new, more powerful preventive treatment for leprosy – which we have named PEP++, with innovative approaches to intensify case detection. The project is targeting six districts of India, Brazil, and Indonesia, as 81% of all new leprosy cases globally are detected in these three countries.

Throughout this project, we expect that 500,000 people will be treated preventatively. The number of new cases within project areas will have dropped by 50% at the end of the project period. With a further continuation of the project beyond that point, we foresee a decrease of 90% by 2030.

The goal is that after further implementation and scaling up of this method (including more countries added as time goes on), the number of new leprosy cases worldwide will decrease drastically.

Given that this bold and challenging project is classified as a clinical trial in the three countries, a long ethical review process was expected. By the end of the year, the Indian Institutional Ethics Committee had approved the protocol, while extensive preparations were still ongoing for clearance in the other countries. The upcoming year brings the blanket campaign in high-burden clusters, effectively launching the new preventive regimen as a tool in the global fight to reach “zero leprosy.”

Much of the work in 2017 was dedicated to starting up activities in:

- Recruitment of technical and field staff
- Ethical clearance of the research protocol
- Identification of how leprosy is perceived and often stigmatised in the communities
- Pilot studies on the use of a rapid screening test to identify leprosy infection
- Mapping of recent leprosy cases to identify “clusters” of cases
LEPROSY POST-EXPOSURE PROPHYLAXIS (LPEP) PROGRAMME
The LPEP (Leprosy Post-Exposure Prophylaxis) research programme is being implemented in eight countries to demonstrate the feasibility of distributing a single dose of the antibiotic rifampicin (SDR) among contacts of people with leprosy, to reduce their risk of developing leprosy. We are involved in the LPEP programme: implementing it in India, Nepal, and Indonesia in close collaboration with our longstanding partners, the Ministries of Health. Novartis Foundation also coordinates and financially supports the programme.

The LPEP programme started in 2015. By 2017, the programme was already well embedded in routine leprosy control programmes in all three NLR-supported countries. Contact screening and the administration of rifampicin is very well received by the persons affected by leprosy, their contacts, and the health workers involved. 2018 will be the final year of the LPEP programme; we will be looking to ensure that this approach is continued in a sustainable way.

SKINAPP
As an organisation, we recognise that there is a scarcity of health workers with sufficient knowledge of skin diseases in the field. Many are often working in poorly resourced settings. This has urged us to come up with a strategy that contributes to a timely diagnosis and treatment, but also increases efficiency and cost-effectiveness of case detection.

A first version of SkinApp was piloted in collaboration with the Mozambican health services, in Zambezia Province in 2015. The positive feedback that we received encouraged us to work on an improved version. It helps to increase the capability of peripheral health workers with no or limited training in dermatology, to become capable of recognising early signs and symptoms of skin diseases. Early recognition and prompt treatment of skin diseases will prevent worsening of the disease and development of disabilities.

The latest version of SkinApp is available in the Google Play Store and the App Store. An upgraded and extended version is currently under development and will be launched in 2018.

SkinApp was the third-placed award winner for The Spindle Best Idea 2017 at the Fourth Partos Innovation Festival in October 2017. The €1,000 cash prize was awarded for the best innovative idea of 2017 in a competition for innovative concepts in international development.

NTD MORBIDITY & DISABILITY (NMD) TOOLKIT
Persons affected by leprosy or other neglected tropical diseases (NTDs) are often stigmatised. This can, in turn, lead to social exclusion and poor mental well-being among those affected. These problems are usually hidden, due to a lack of data and information that would make them visible.

We have continued to put together a toolkit of instruments for measuring disease complications, disability, stigma, and mental well-being of persons affected by leprosy and other NTDs, called the NTD Morbidity & Disability (NMD) Toolkit. Some of these tools were used to collect data on leprosy-related stigma in Brazil, India, and Indonesia. These studies revealed high levels of stigma, which will be addressed as part of the Dream Fund Project that started in 2017. The NMD Toolkit is available free of charge to the NTD community around the world through InfoNTD.org.

“I was diagnosed with leprosy during the LPEP programme. I want this programme to reach every village and make people aware of it, and I would tell people that it is a disease that can be cured.” Khemraj Sigdel (32) from Jhapa in Nepal.

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Sharing our knowledge & experience

Infolep is a key resource for information on leprosy and related subjects. The portal offers access to 27,300 publications, with 1,000 publications added in 2017. The Infolep portal is used by 22,393 people across 185 countries. Based on the success of Infolep, a new portal was launched in 2016: InfoNTD, providing information on cross-cutting issues. In 2017, its first full year, InfoNTD had an impressive 10,000 unique visitors.

The portals offer support upon request, such as library services: full texts of published articles, grey literature, and assistance with literature searches. Comprehensive, current information can be found on key topics on the Infolep portal and specific cross-cutting issues on the InfoNTD portal. Tools for fieldwork, such as questionnaires, are also available on both portals.

Both portals are supported by partner organisations. In 2018, user surveys will be carried out to further improve the services these portals have to offer.
In 2017, the Netherlands Leprosy Relief (NLR) was active in Mozambique, India, Indonesia, Nepal, and Brazil. We are currently phasing out our work being carried out in Nigeria and the Mekong Region.

The situation is different in each country and each individual issue requires attention. Our approach, therefore, is always tailored to the specific circumstances and needs. In one country we may focus on the identification and treatment of leprosy, however, another country may require more support around disability and inclusion. The largest numbers of new leprosy cases were found in our programme areas in India, Brazil, and Indonesia.
**MOZAMBIQUE**

Country statistics, the 2017 situation

Number of new cases reported: **1,926**

% of new leprosy cases with grade 2 disabilities: **9.8%**

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**OUR RESULTS**

What have we achieved in Mozambique?

- **1,437** new leprosy cases were found, diagnosed and treated in our programme areas.

- **329** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability care.

- **29** existing self-care groups (formed before 2017) and **35** newly formed self-care groups were supported.

- **8,583** people from communities were informed and educated on general disabilities to raise awareness.

- **214** health workers, community volunteers and government health staff were trained on leprosy.

- **420** men underwent a hydrocelectomy, a surgery to reduce swelling of the scrotum.

- **880** people were informed and educated about leprosy to raise awareness.

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

- **3** Disabled People’s Organisations (DPOs) received assistance to promote participation of people with leprosy-related disabilities.

- **1,137** persons with disabilities were oriented on their rights — so that they can claim them.

- **2,984** people were informed and educated on general disabilities to raise awareness.

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**Country statistics, the 2017 situation**

- **Number of new cases reported:** 1,926
- **% of new leprosy cases with grade 2 disabilities:** 9.8%
“I now get the help I need”

In June 2017, Lidia (35) was diagnosed with leprosy. She finally knew what had been causing her problems. “Unfortunately, it was far too late. My deformities cannot be reversed. It pains me. I am looking forward to joining the new self-care group that is starting in my neighbourhood soon. I will meet fellow sufferers there who are going through the same things as I am.”

“It started with ulcers on my hands, knees and feet. They simply did not get any better. I decided to see a traditional healer, but he did not know what to do. In the meantime, my body became increasingly damaged. Especially my nose, cheeks and ears. I found myself repulsive. My husband left me and all of a sudden, I was on my own with my four-year-old daughter. That was difficult and tough.”

QUESTIONS ANSWERED

“One day I met Alberto, the community volunteer. He strongly suspected I had leprosy. He took me to the local health centre, but they found it difficult to come to the right diagnosis. I went home with the same questions haunting me. What was wrong with me?

Alberto told me a leprosy day was coming up in our village. He insisted that I go, because the district hospital leprosy doctor would be there. He would be able to examine me that day, which he did, thoroughly, and he immediately diagnosed me with leprosy. Finally, all the question marks disappeared, now I knew. I was given the right medication straight away. I felt relieved; he could cure me.”

FINDING COMMUNITY

“I diligently take my pills, because I want the disease to go away. My deformities cannot be reversed though. That pains me, but I am trying to learn to live with it. Sometimes I am sad that I do not have any friends I can go to. Then I feel lonely and excluded.

Alberto has taught me how to best look after my ulcers so that I do not get any more permanent damage to my skin. He keeps an eye on me. I am getting better. Soon a new self-care group will start in our village, so I can go to the monthly meetings. I am very much looking forward to that. I will learn more about self-care and I will belong to that special group. I think it will be nice to be among fellow sufferers. They are going through the same things.”

Community volunteer Alberto (48):

‘I put my heart and soul into it’

“The community appointed me as a volunteer. I do not have leprosy myself, but I put my heart and soul into it. I want to help my fellow villagers, it means something to them. I trace new leprosy cases, make sure they get and take their medication. I teach them how to best treat their ulcers. I am very happy a self-care group is going to start in our area. It will do them good.”
SkinApp

The first version of SkinApp was field tested in Mozambique. Based on the feedback received from the peripheral health workers, a second version was developed. In 2017 the pilot project with the second version of SkinApp started, in provinces Zambezia, Nampula and Niassa.

RESULTS IN 2017
• 18 health technicians and 8 district chief doctors were familiarised with the use of SkinApp in a training session.

LESSONS LEARNED IN 2017
• The use of SkinApp contributed to improvement in skills of the users, early diagnosis and correct and prompt treatment.
• It also led to more intensive sharing of experiences and knowledge through a supporting WhatsApp group that was set up.

PLANS FOR 2018
• The lessons learned from the pilot project will be used for the updated version of SkinApp that will come out in 2018.
STORY FROM THE FIELD

“SkinApp has improved my speed of detection and enables me to get the patient treated timely”

Victória José Alexandre (29) works as a nurse at a health centre in Nampula. Since she started using SkinApp, it is much easier for her to make diagnoses. It has significantly improved her work.

“The Chief Doctor, Dr Quenésio talked to all the health centre staff about the leprosy programme and SkinApp. I was interested in it and I asked him to download the app on my mobile phone for me. Gradually I became familiar with it and realised its advantages.

SPENDING LESS TIME RESEARCHING

Before, I used to make the diagnosis of my patients empirically and would rely on the literature and pictures from my course books to draw a conclusion. This was time-consuming for me as it required extra time to research at home after office hours. For example, I used to test the patients and prescribe them medication, but afterwards, they would immediately return to the health centre because they were not getting better. Trying to check what the doctor said one day, in one of the consultations I received a child and using SkinApp, I diagnosed him with the skin condition Bullous Impetigo. I prescribed the medication and continued to use SkinApp as a tool during the follow-up. The child got better and now she is discharged from the hospital.

The app has greatly improved my work in terms of detection quickness. It enables me to immediately give the correct medication enabling the patient to be treated timely. Because of this app, I spend less time researching to find out what disease the patient is suffering from before I refer them to other nurses.”
Combined approach lymphatic filariasis (LF) and leprosy

Since 2015, we have been working on a combined approach with funds from UK-based ILEP member Lepra, addressing the needs of persons affected by and at risk of LF and leprosy in Zambezia province. The combined approach is intended to prevent persons affected from developing impairments and/or manage their impairments and disabilities themselves, with secured access to the services they need. In this project, the capacity of government staff is strengthened. Community volunteers are trained on leprosy and management of LF. We are currently working with fifty-nine combined self-care groups with a total of 1,134 members (724 men and 410 women).

RESULTS IN 2017
• 2017 was marked by an increased involvement from members of self-care groups working to detect new cases.
• Most of the leprosy cases were detected without any visible deformity. This is an encouraging improvement; it indicates an increase of knowledge among volunteers and successful early diagnoses performed by health staff.
• Due to mobilization by NLR in the target area, the Ministry of Health took up the financial and technical support of the hydrocele surgery activities. 420 men underwent a hydrocelectomy to reduce swelling of the scrotum.

LESSONS LEARNED IN 2017
• Involving community volunteers is absolutely crucial in mobilising people using a combined approach.
• This approach is effective in increasing access to information for poor people in rural areas, as well as providing different health services at the same time, without being limited to one disease.

PLANS FOR 2018
• In 2018 a final evaluation is planned.
• We will explore other funding opportunities to reinforce the work done through this project.
• We will look at replicating the best practices and evidence-based lobby and advocacy.

António (58) suffered severely from leprosy. His hands and feet became deformed and his eye muscles too were affected. On top of that he got infected with lymphatic filariasis, causing his scrotum to swell. He refuses to let this grind him down however; he is now a volunteer and the leader of a self-care group in his village. “I want to spare fellow sufferers the misery.”
“In the self-care group I am looking after myself and others”

Belinha Carlos (35) became unknowingly infected with lymphatic filariasis. She suffered from severe pain in her feet and could not walk properly, until community volunteer Eduardo took her to the health centre and invited her to join the combined self-care group in her village.

“One day, in an alley full of grass, as I was on my way to the garden, I felt like something was cutting my feet. At that moment I did not take that into account, because I thought that a straw had touched me and made up that scratch. A week later, I started to suffer from severe pain, my feet swelled up and I could not walk properly. I went to the health centre where I was checked, but the nurse said she did not know what that swelling was. She asked me whether I had done some traditional treatment, to which I replied ‘yes’. She prescribed me some tablets. Even after taking the medication I was not getting better. I spent three months ill; I was not even able to walk to the farm or do other household activities.”

NO MORE PAIN

“A neighbour of mine visited me and told me about the self-care group. The next day, a community volunteer called Eduardo, who is the group leader, paid me a visit. He gave me some advice and took me to the health centre once again. There the doctor prescribed other medications. I am better now, but the swelling in my leg has not gone away yet. My foot does not hurt any more thanks to that medication. I can go to the farm, fetch water, go out to chat with my neighbours and make love. Before treatment, I could not do that."

INVITING OTHERS TO JOIN

“In the self-care group, I learned a lot about the importance of personal hygiene – taking a bath, managing the trash, building latrine, and also about leprosy. Because of the benefits I was getting from the group, I decided to invite my neighbour Fatima to join it after seeing a spot on her arm. When I told her about it she explained that she had been having some pains in the same arm. Fatima was diagnosed with leprosy and is now undergoing treatment. I am very grateful for this programme and as I am still alive, I will keep inviting more people to the group, so they can have the treatment and learn many things about it just like I have.”
Disability-inclusive villages

NLR Mozambique identified two locations in Nampula and Niassa province. Two Disabled People’s Organisations (DPOs), ADEMO and FAMOD, are working there to set up pilots of disability-inclusive communities. NLR staff from Mozambique and ADEMO staff were trained in Indonesia on the use of participatory tools that can be used as a baseline for disability inclusiveness.

RESULTS IN 2017

• Partnerships were set up and training was given to two DPOs (ADEMO and FAMOD) enabling them to set up a disabled-inclusive communities pilot project in Nampula and Niassa province.
• NLR’s approach of sharing experiences and raising awareness on disability-inclusive development resulted in a strong commitment of the Ministry of Gender, Child, and Social Affairs to work with NLR.

LESSONS LEARNED IN 2017

• Active involvement and commitment from local governmental departments is essential in work on inclusion in rural communities.

PLANS FOR 2018

• Staff of the two DPOs will be trained to gather data in a participative baseline survey.
• Information from the baseline will be used to implement the pilot of the Disability-Friendly Community in two villages in Nampula and Niassa.

NLR Mozambique took part in an exchange visit to Nepal to learn from their experiences on working towards disability-inclusive communities. Meetings with different stakeholders were held to share their experience, raise awareness on disability-inclusive development and to generate interest in setting up a similar project in Mozambique.
What have we achieved in India?

- **37,795** new leprosy cases were found, diagnosed and treated in our programme areas.
- 172 people’s lives were changed with reconstructive surgery.
- **7,303** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
- **1** Disabled People’s Organisation (DPO) received assistance to promote participation of people with leprosy-related disabilities.
- **1,887** health workers, community volunteers, accredited social health activists (ASHAs), and government health staff were trained on leprosy.
- **3,201** persons with disabilities were oriented on their rights – so that they can claim them.
- **7,303** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
- **1,659** people were informed and educated about leprosy to raise awareness.
- 7 people received a microcredit to help them become self-employed.
- **563** existing self-care groups (formed before 2017) and **10** newly formed self-care groups were supported.
- **325** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability care.
- **1,290** children of leprosy-affected persons received financial support for their education.
- **729** people were provided with leadership training.

**Country statistics, the 2017 situation**

- Number of new cases reported: **135,487**
- % of new leprosy cases with grade 2 disabilities: **3.87%**
“I will no longer be called a child of a leper”

Guddhu (23) was born and raised in a leprosy colony in Delhi. Since his eighth standard, he received financial support for his education. Now, after graduating with high marks, he has got a good job at the domestic airport. With his salary, he can build his own life outside the colony.

“My parents had to leave their native place Bellor, Karnataka 27 years ago. They were discriminated in the community and had no means of livelihood. During this time, my father had come to know from his friends that many people affected by leprosy were living in leprosy colonies. He decided to migrate to Delhi with my mother and made the leprosy colony his new abode.

BEGGING TO SURVIVE
Life continued, my parents survived with whatever they could get from begging to take care of five siblings, of which I am the youngest. My only sister was married and is now a widow living in the colony. She is working as a cleaner in place of her husband. My three bothers hold private jobs with acute salaries as daily wages. This amount is insufficient, but they are still managing as they live with their father. Only I continued my studies.

BUILDING A SOLID LIVELIHOOD
I feel proud to say that NLR came as a ray of hope in my life. NLR has been supporting me under its education programme since my eighth standard. My school fees were paid and I was provided with a uniform, school bag, books, and stationeries. I completed my BA in Political science with 53% marks and with the efforts of NLR I was selected for a Cargo Basic Management course at GMR Foundation, Dwarka. This is a reputed institution with 100% placement. I am now employed at the domestic airport with the salary of 18,000 Rupees per month. This amount is enough to take care of my needs and save some money to buy a house outside of the colony. This will give me an identity in the mainstream. I no longer need to face discrimination and will no longer be called a child of a leper.”
Leprosy Post-Exposure Prophylaxis (LPEP) programme

The LPEP programme in India is being implemented in Dadra and Nagar Haveli (DNH). The project is very well integrated with the routine Leprosy Control Programme in DNH, which involves multiple active case-finding activities per year.

RESULTS IN 2017

• Around 30,000 contacts were given rifampicin since the project began in 2015. In 2017, this concerned 5,545 contacts.

LESSONS LEARNED IN 2017

• These results have led to the Central Leprosy Division (CLD) issuing operational guidelines for Post-Exposure Prophylaxis (PEP) that were developed alongside NLR’s technical input. The guidelines are operational in 163 districts of twenty states where leprosy case detection campaigns were carried out in 2016. This led to an impressive total of 58,674 contacts who were given rifampicin in those districts in 2017.

PLANS FOR 2018

• As in 2017, together with other ILEP (International Federation of Anti-Leprosy Associations) partners, NLR will be involved in ensuring the quality of the implementation in 2018.
Dream Fund Project: Stop the Transmission of Leprosy!

The Dream Fund Project in India is focused on two districts: Fatehpur and Chandauli. Given that this project is classified as a clinical trial, a long ethical review process was expected.

RESULTS IN 2017
- India was the first country to obtain ethical clearance of the “Stop the Transmission of Leprosy!” project, as the full research protocol was formally approved on 7 December 2017 by the Institutional Ethics Committee. It was also recognised by the university partners at Vardhman Mahavir Medical College/Safdarjung Hospital for implementation with its support.

LESSONS LEARNED IN 2017
- India was also home to the only complete perception study in Fatehpur district, including interviews with the full range of index patients, contacts, and healthcare workers. This led to several changes in the overall perception study research protocol, based on the field experiences.

PLANS FOR 2018
- In early 2018, the India programme will undertake the mapping of the index patients from 2014 to 2017, leading to cluster risk map production and the control/intervention areas.
**STORY FROM THE FIELD**

**“I am glad I have seen my daughter cured”**

Nearly one in eleven of all newly diagnosed leprosy patients are children. The incidence of leprosy among children is indicative of active transmission in the community. Subi (7) became infected by leprosy when she was just four years old. She completed the multi-drug therapy (MDT), but the loss of sensation in her left hand cannot be reversed. To prevent disability, she is participating in a self-care group. It is very important that she does not get any wounds on her hand.

**A DAUGHTER’S JOY SILENCED**

“My daughter was a major chatterbox. She would joke with the neighbour and sing songs with the owner of the vegetable stall on the corner of the street. She always knew exactly what was going on in the neighbourhood. My daughter was anything but shy.

Until one day, when she heard that she had leprosy. The spots on her face would not go away anymore. From then on, she became silent. My most beloved daughter become a totally different, silent girl; scared of being different to the other children.

**TOO LATE**

It started three years ago. My daughter Subi got patches on her face. I did not know what it was. In my area, nobody recognised the symptoms. After about a year, an uncle came by me. He told us that it could be leprosy. I was shocked and so went to the hospital with Subi. There my uncle’s suspicions were confirmed. From the doctors in the hospital, Subi received a one-year multi-drug therapy. But despite the medicines, sadly her hands began to deteriorate and the spots remained. We were too late.

**MOVING FORWARD**

Subi is now seven years old and is attending a self-care group. There she receives physical therapy to help her hands move better. But in her left hand, she has no feeling at all. It is therefore very important that she is careful and doesn’t get any wounds on her hand.

She is attending school and I do not think she is being bullied there. I am so glad to see my daughter cured and I am confident she will speak again one day.”
Combined approach lymphatic filariasis (LF) and leprosy

Combined self-care projects were started in ten Primary Health Centres in 2017. People affected by leprosy and people LF were trained together in self-care.

RESULTS IN 2017
• 325 people with disabilities joined. In 100% of cases, the worsening of disabilities was prevented.

LESSONS LEARNED IN 2017
• NLR is the first organisation in India to experiment with this combined self-care approach. While we are taking the initiative and giving initial guidance, the staff of the Health Centres took up their role as supervisors.

PLANS FOR 2018
• This makes it a promising innovation, which can be continued by the Primary Health Centres themselves. Only minimal supervision may be needed by external technical experts.
Strengthening Disabled People’s Organisations (DPOs) and Self-Help Groups (SHGs)

NLR’s initiative of bringing together persons affected by leprosy and those with disabilities, to work together in self-help groups for social and economic independence and rehabilitation expanded in 2017, in collaboration with a local partner DPO.

RESULTS IN 2017
• Of 198 self-help groups that were formed in Aurangabad district of Bihar, 168 groups now have a bank account and 154 have developed business plans.
• Through this process, 278 families have been able to start generating income in 2017.
• One of the activities they undertook was to take part in a march to raise their voices and place their demands before duty bearers. As a result, disability certificates were issued to persons with disabilities, so that they can claim benefits from the state government.

LESSONS LEARNED IN 2017
• The evaluation of the overall programme pointed out that it would be good to reflect on the stabilisation of results from these groups before expanding further.

PLANS FOR 2018
• Expansion will happen in other districts based on the good results of the first batch.
INDONESIA

Country statistics, the 2017 situation

Number of new cases reported: 16,826
% of new leprosy cases with grade 2 disabilities: 8.1%

Our Results

What have we achieved in Indonesia?

14,363 new leprosy cases were found, diagnosed and treated in our programme areas

10,517 direct contacts of new leprosy patients given a single dose of rifampicin (SDR) to reduce the risk of developing leprosy by 50-60%

118 people were informed and educated about leprosy to raise awareness

1,630 people from communities were informed and educated on general disabilities to raise awareness

3 existing self-care groups (formed before 2017) and 2 newly formed self-care groups were supported

30 persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability care

47 people’s lives were changed with reconstructive surgery

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

275 persons with disabilities were oriented on their rights so that they can claim them

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

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

352 people received vocational training to learn a trade

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

75 people were provided with leadership training
“By sharing our experiences with leprosy, our little island is now free of stigma”

Jacob David (44) grew up and still lives on Bunaken, a small island off the coast of Northern Sulawesi. It has a population of nearly 3,000 people. We have been paying yearly visits to the island to locate new patients and to educate the islanders on leprosy. Thanks to the recurring visits, the stigma around leprosy has disappeared and the disease is under control. Over the past three years, only one new case of leprosy has occurred.

AFRAID OF BEING STIGMATISED

“I was only a little boy of thirteen when I got skin sores on my arms - my skin was red. ‘Auntie, my arms look funny,’ I said. She was shocked. We went to a hospital on a different island. The doctor examined me and gave me medication, but that didn’t work. Why didn’t the sores go away? What was I supposed to do?

I grew up to be an adult with terrible insecurities. I thought I had leprosy, but I wasn’t sure. I was ashamed and afraid of being stigmatised. I did not dare tell anybody, not even the woman I married. I numbed myself with booze and kept bad company.

I went from bad to worse, I felt so alone. My skin turned darker and darker, my fingers were becoming crooked. But I hid it from everybody. If only I had asked for help sooner. If only I had had the guts to share my discomfort.

HOPE IN THE DARKEST PLACE

But in my darkest, loneliest hour, my fortune changed. Somebody appeared at my door. ‘I am from the island’s new health centre, I am here to help you.’ My data had been forwarded, and it was not until then that I was formally diagnosed with leprosy. And with the right medication, I was cured. Finally, I was cured of the disease. I felt liberated.

I used to fish for tuna in the deep waters around the island, but I anticipated better economic chances for myself as a local boat builder and repairman. Myself and my family are checked for symptoms of leprosy every year, but I wanted to do more.

DEFEATING THE STIGMA

I am now the chairman of the island’s self-care group. There are thirteen of us and we are all former leprosy patients. We assist health workers in finding new leprosy patients. Furthermore, we talk with each other about the disease and we help each other to treat our wounds.

That includes the invisible wounds. By sharing our experiences with the disease, our little island is now free of stigma. Now no one needs to feel ashamed the way I did for so long.”
Leprosy Post-Exposure Prophylaxis (LPEP) programme

The year 2017 is the third year of implementation of the LPEP programme. Rifampicin was distributed in all health centres (22) in Sumenep district on Madura Island, East Java.

RESULTS IN 2017
• 10,517 contacts received rifampicin in 2017.
• In Sampang district, also on Madura Island in East Java, the distribution of rifampicin started in 2012. By 2017, 11,157 contacts of 600 index cases were given rifampicin.
• Another location where the LPEP programme has been implemented is Linggat village (Maluku), which is located on a remote island that can only be reached by boat in favourable weather conditions. On this island, because of the high number of leprosy patients, all inhabitants were treated with rifampicin in 2015 and 2016.

LESSONS LEARNED IN 2017
• India was also home to the only complete The different approaches used for the distribution of rifampicin provides us with valuable information about the most feasible approach in a variety of circumstances.

PLANS FOR 2018
• In 2018, three years after the start of the project, our focus will be on ensuring the sustainability of the activities.
Dream Fund Project: Stop the Transmission of Leprosy!

In 2018, NLR Indonesia set the foundation for this innovative programme together with its partners in the federal Ministry of Health, the East Java Provincial Government and Airlangga University. The wide range of project initiatives will take place in the districts of Pamekasan and Pasuruan over the next five years.

RESULTS IN 2017
- Indonesia conducted the original screening test pilot study in May 2017, with follow-up testing occurring in August.

LESSONS LEARNED IN 2017
- The team revealed important results, showing that the OnSite Rapid Test did not perform as well as expected in detecting subclinical leprosy. University partners consequently carried out additional ELISA tests, which revealed there to be no significant statistical correlation between the ORT and ELISA results. This was an essential part of defining the overall PEP++ study design.

PLANS FOR 2018
- Ethical clearance for the general protocol is expected in early 2018.
Leprosy-Friendly Villages

After five years of implementing the Leprosy-Friendly Villages programme in North Minahasa, we are extremely pleased that major successes have been achieved.

RESULTS IN 2017
• The programme has successfully reduced the number of new leprosy cases in its area of operation. In addition, the percentages of child cases and disability grade 2 cases among newly detected cases have decreased significantly.

• The positive behaviour of the Health Centre staff and ownership shown by the local government is very supportive.

LESSONS LEARNED IN 2017
• In order to increase the impact, with the success of LPEP (Leprosy Post-Exposure Prophylaxis) in mind, the Leprosy-Friendly Village approach will be scaled up – with SDR (single dose of rifampicin) implementation.

PLANS FOR 2018
• Funding by the local government has gradually increased. In 2018 they will fund the larger portion of the activities.
Capacity Strengthening on Disability-Inclusive Development

This year, NLR Indonesia has strengthened the capacity of nine NLR partner organisations (six Disabled People Organisations, two Civil Society Organisations, and one Government partner) on project cycle management, lobby and advocacy, and rights-based approaches.

RESULTS IN 2017
- All partner organisations have improved their involvement in lobby and advocacy in their areas of operation (either village, sub-district, or district) and towards the local government. This varies from training sessions on public speaking for members of self-care groups; support to registration for national ID cards; economic empowerment activities; stakeholder meetings to advocate for the rights of persons affected by leprosy and persons with disabilities; to advocating successfully for integrated care for HIV/AIDS, tuberculosis, and leprosy.

LESSONS LEARNED IN 2017
- Training on project and organisational management was conducted for partners, but there are still challenges around how to practice and implement this in their organisations. Therefore in 2018, there will be activities to review and advance their capacity through specific organisational management/financial training.

PLANS FOR 2018
- Continue capacity building with the internal NLR team and partner organisations on using participatory evidence-based and rights-based approaches.
Mobile Leprosy Information (MLep)

This IT-based project, funded by ILEP member effect:hope, aims to provide mobile information to help prevent disability due to leprosy.

RESULTS IN 2017
- 2017 was the final year of this project, in which various activities and tools were developed. This year saw the making of two films on self-care. E-learning apps for health workers and apps for provincial administrators and health workers to update client data were developed, which greatly improved accuracy. The SMS Gateway has been integrated with the MLep database. The M-Lep Facebook page had 695 members by the end of 2017.

LESSONS LEARNED IN 2017
- In 2018, the project will be externally evaluated.
Disability-Friendly Communities

The NLR multi-country KPP3 programme (Disability-inclusive development) has started off this year, with the aim of developing Disability-Friendly Community models. There are preliminary activities happening in Indonesia.

RESULTS IN 2017
• The Indonesia KPP3 task force was established. This happened following a consultation meeting with partner organisations. The task force consists of five representatives from partner organisations and three from NLR.

• It has been agreed that the model will be developed in Cirebon (West Java) and in Jeneponto (South Sulawesi).

LESSONS LEARNED IN 2017
• A study visit was paid to a Leprosy-Friendly Community in North Sulawesi. In December 2017, NLR Indonesia hosted the KPP3 multi-country workshop, in which the baseline tools were tested. This took place in Cirebon, West Java. Translation and modification of tools continue to be required, based on local country needs and culture.

PLANS FOR 2018
• Baseline and follow-up activities are planned for 2018. The specific content of the activities will depend on the outcome of the baseline.
## NEPAL

### Country statistics, the 2017 situation

Number of new cases reported: **3,215**  
% of new leprosy cases with grade 2 disabilities: **2.7%**

## OUR RESULTS

### What have we achieved in Nepal?

- **910** new leprosy cases were found, diagnosed and treated in our programme areas.
- **12,328** direct contacts of new leprosy patients given a single dose of rifampicin (SDR) to reduce the risk of developing leprosy by 50-60%.
- **435** health workers, community volunteers and government health staff were trained on leprosy.
- **371** people from communities were informed and educated on general disabilities to raise awareness.
- **1,244** persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability.
- **173** existing self-care groups (formed before 2017) were supported.
- **105** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
- **70** Disabled People’s Organisations (DPOs) received assistance to promote participation of people with leprosy-related disabilities.
- **404** people received a microcredit to help them become self-employed.
- **25** people were provided with leadership training.
- **329** persons with disabilities were oriented on their rights—so that they can claim them.
- **12** people’s lives were changed with reconstructive surgery.
- **105** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
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- **105** people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses.
Leprosy Post-Exposure Prophylaxis (LPEP) programme

The LPEP programme has been implemented in three districts of Nepal: Jhapa, Morang, and Parsa, which are all located at the southern border with India.

RESULTS IN 2017
• Since the start of 2015 until the end of 2017, a total of 45,480 contacts of 2,013 index cases received rifampicin (SDR), lowering their risk of developing leprosy.
• A decrease in the number of new cases is now evident in the project districts.

LESSONS LEARNED IN 2017
• Health workers are motivated to distribute rifampicin (SDR) as it involves actively screening the contact, which leads to early identification on new patients. It also provides them with something to offer the contacts that helps to prevent the development of the disease.

PLANS FOR 2018
• The results of the project have inspired the government of Nepal to expand the LPEP approach into another six districts where leprosy is highly endemic. NLR will provide the technical support to enable this upscaling and will be involved in training, monitoring, and supervision.
• Other plans are being developed to adapt the approach to areas where leprosy is less prevalent.
“It is much better to prevent the disease than treat it after”

Rohit Bastola (61) from Jhapa was diagnosed with leprosy in October 2017. Just a few days after the diagnosis, the first LPEP survey of his family and the people in his surroundings took place. Many people dropped in gradually throughout the morning and the LPEP team examined over eighty people in the two hours that they were there.

**MYSTERIOUS BODY PATCHES**

Rohit lives with his wife Gomadevi, their two sons, his son’s wife, and two grandchildren, nine-year-old Samikshya and fourteen-year-old Sandesh. They have a family shop that sells general groceries and also has a tea garden.

Though Rohit was diagnosed less than a month ago, he has had patches on his body for a year and a half, at first on his legs and later on his left arm. Soon after he noticed the patch, he realised that it had gone numb.

“At first, I just went across the border to India and got some ointment for it.” But nothing much happened, and Rohit left it, until about a year later a similar patch appeared on his elbow.

“I was lucky”

After that time, a distant relative saw the patch and recognised it, as his son previously had leprosy too. He recommended Rohit to go to the local hospital. It was there that Rohit was diagnosed with leprosy. He started treatment at the local health post the next day.

“My sensation is already recovering.” He says. “I was lucky though, it never really affected my daily life. I had tingling sensations on my feet, but it did not really disturb my activities. I had heard of leprosy but did not really know any details. I remember seeing a person in the tea gardens with some deformity, but I do not know whether that was due to leprosy. I do not know why this has happened to me; I am a vegetarian, I do not drink alcohol… Before I was diagnosed, I did not think too much of this. But now I have been taking the medicine for one month, it feels like it is leprosy. I do worry that it might affect me in my old age, or I might die of it. I really like the LPEP survey, it’s much better to prevent the disease than treat it after. I hope these things that happen to me will not happen to others in their lives. I am just going to make sure I take this medicine for a year.”

Jiwan, Rohit Bastola’s son

“I am thankful, people from all over came together to organise the LPEP survey programme at my home. It was very difficult ages before, but there is medicine for the disease now and I am taking it. I wish this programme will help prevent spreading of the disease.”
HIGHLIGHTED

Disability-Friendly Communities Model

NLR Nepal has been working for some years on a Disability-Friendly Communities (DFCs) model. In this concept, the communities, government agencies, and other relevant stakeholders become responsible and accountable towards fulfilling the rights of persons with disabilities, including persons affected by leprosy, as provisioned in laws, policies, and programmes. Persons with a disability should be integrated fully so that they can play an active part in society and lead a normal life.

This model serves as an example for NLRs work on disability-inclusive development in India, Indonesia, Brazil, and Mozambique. NLR staff from these countries visited the Nepal DFCs. An evaluation of the programme in Nepal was done to document the model and indicate the best practices to feed into NLRs KPP3 programme worldwide.

RESULTS IN 2017

- By the end of 2017, NLR Nepal had successfully established four DFCs, although they are still at different stages of development.
- In service delivery, 404 people with leprosy and disabilities were provided with livelihood support and over 463 received medical and surgical help.
- The local Government has accepted the concept of DFCs and incorporated it into its multi-annual and annual planning.

PLANS FOR 2018

- The DFCs project will be extended to nine additional municipalities.
- Agreements will be made with municipalities to guarantee their commitment, including a financial contribution towards setting up the DFCs.
- The model we used in Nepal will serve as a template for setting up DFCs in four other NLR countries.

LESSONS LEARNED IN 2017

- The external evaluators of this project indicated some key factors contributing to the success of the DFCs:
  - Support at the political level is seen as essential for this programme.
  - The high level of participation in the programme caused the community to feel a sense of ownership.
  - Disabled people (including those affected by leprosy) are more visible and active in community life, resulting in positive behaviour change and less discrimination.

“Previously, persons with a disability were bullied, but this has now reduced. They can now access public spaces, have been provided with wheelchairs and as a result they can participate more in community life. They appear to be happier and are smiling more.”
- Female Political Leader, Jante.
BRAZIL

Country statistics, the 2017 situation

Number of new cases reported: 25,218
% of new leprosy cases with grade 2 disabilities: 7.9%

OUR RESULTS

What have we achieved in Brazil?

- 24 existing self-care groups (formed before 2017) and 3 newly formed self-care groups were supported
- 560 persons disabled by leprosy and other diseases were trained in self-care to help prevent (further) disability care
- 4,415 new leprosy cases were found, diagnosed and treated in our programme areas
- 450 health workers, community volunteers and government health staff were trained on leprosy
- 5,366 people were informed and educated about leprosy to raise awareness
- 217 people from communities were informed and educated on general disabilities to raise awareness
- 217 people from communities were informed and educated on general disabilities to raise awareness
- 110 persons with disabilities were oriented on their rights so that they can claim them
- 8 people’s lives were changed with reconstructive surgery
- 3,745 people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses
- 40 people were provided with leadership training
- 79 people received vocational training to learn a trade

Country statistics, the 2017 situation

Number of new cases reported: 25,218
% of new leprosy cases with grade 2 disabilities: 7.9%
‘I learned to love myself again’

“I was in the prime of my life. Every night after work, I was out in the neighbourhood. My husband was proud to have me as his wife. He was joking about it and told me that I was Brazil’s most beautiful woman. Until the moment I got leprosy. My husband left me and I was being chased out of the street. This is not the life I want.”

20 DIFFERENT DOCTORS

“Before I got leprosy, I often went to the beach, everything was great. I had a busy social life, a nice job and enough money to go out. Then, in 2009, I started to have all kinds of medical complaints. The feelings in my fingers declined, my lips started to swell and I often got a fever. Nobody knew what it was, neither my friends nor my doctors. Because it often felt like I was burning, I went to a lot of doctors. Twenty doctors in total. But none of them could tell me where that feeling was coming from. Until I heard in a special clinic – Santa Casa de Misericórdia – that it was leprosy. I received a yearlong treatment from the doctor and the advice not to talk to anyone. Then I would possibly lose all my friends.

NOBODY CARED ABOUT ME

The most terrible time of my life began. When I told my husband, he laughed at me and left. I never saw him again. My sister took me into her home because I was desperate.

Because of leprosy, I had several injuries. They became so bad that at one point I had to be hospitalised. I spent two months alone there. Nobody picked me up, even on my birthday. It still gives me chills when I remember that time. I was extremely depressed, I only wanted one thing... death.

After being discharged from the hospital, I returned to my family. It got worse. I had to tell them that I had leprosy and that it was being treated. When they heard about it, they did not want anything to do with me, so even they turned their backs on me! It was terrible!

MY RESCUE

Fortunately, a doctor told me about a self-care group. That was my rescue. I finally got some answers to all of my questions. I also found support in the church, I go there at least twice a week. Praying gives me strength and peace. My situation finally turned around and I learned to love myself again.

Now I am ready to help others in the self-care group. I give answers to questions that I used to have myself. It is a really good feeling. Despite the misery of my experience, I know that I will never go there again. My family will never see me again, but I do not want to die anymore, on the contrary, I see a bright future. It can only get better.”
Dream Fund Project: Stop the Transmission of Leprosy!

In October 2017, Brazil obtained approval to conduct a screening test pilot study as part of the project. Soon thereafter, the team at the Federal University of Goiás began the laboratory component of the pilot study, which will help determine if it is possible to use a rapid test in any of the countries during the study.

RESULTS AND LESSONS LEARNED IN 2017

• The team examined serum samples of leprosy patients and their contacts using ELISA and an enhanced lateral flow (ML++) test. Unfortunately, it has not yet been possible to compare these results with the original OnSite Rapid Test due to import restrictions.

PLANS FOR 2018

• This testing should be completed in early 2018, in time to help define the overall project methodology. Soon thereafter, we expect to have overall ethical clearance for the clinical trial in Brazil.
HIGHLIGHTED

(Combined) self-care groups
Fostering and propagating (combined) self-care groups has continued in 2017.

RESULTS IN 2017
• At the start of the year there were twenty-seven groups, a number which has significantly increased to a total of fifty-nine groups by the end of the year.

LESSONS LEARNED IN 2017
• Many groups that were previously financially supported, continued without financial support this year. The Brazil team was able to provide technical support in cases where groups expressed a need.

PLANS FOR 2018
• In 2018, NHR (Netherlands Hanseniasis Relief*) will pilot the testing of a tool that they developed to monitor the impact of these groups.

*In Brazil leprosy is referred to as Hansen’s Disease.
Development and validation of stigma and empowerment scales

NHR Brazil gave support to a project in partnership with the Federal University of Ceará, to conclude the adaptation and transcultural validation of EMIC Individual, Community, and Empowerment scales.

RESULTS IN 2017
- The scales have been validated specifically for use with persons affected by leprosy, other neglected tropical diseases, and their communities.

LESSONS LEARNED IN 2017
- Validation of the scales took quite a lot longer than we expected.

PLANS FOR 2018
- The scales will be used in a project for strategy development on stigma reduction and in the Dream Fund Project in 2018.
After seeing a structural decrease in our income, in November 2016 we decided to phase out funding to two of our offices: NLR Nigeria and NLR Mekong. We were then approached by both teams with their plans to continue functioning as a local NGO, without NLR funding. With both offices, we agreed on a transition plan of two years, in which some programmes will be ended and for others, alternative financial support is being sought.

THE TRANSITION PHASE

Nigeria

As part of the process of NLR’s exit from Nigeria, we implemented a “legacy project,” to build on two innovative approaches that NLR Nigeria has developed over the last few years.

1 By involving traditional healers, community volunteers, and patent medicine vendors in recognition and referral practices within low endemic areas, we have seen successful referrals and an increase in the number of cases found.

2 The “slimmer and smarter” approach on leprosy control has resulted in a more cost-efficient and effective leprosy control organisational set-up. Under this approach leprosy services increasingly focus on fewer health clinics where multi-drug therapy (MDT) is provided, with better-trained General Health Workers in the General Hospitals and a few Primary Health Centers (PHCs)

Preliminary results on case-finding at the end of 2017 show that a total of 793 new cases in three states have been detected and are receiving treatment. This number is already well beyond the target set to detect 625 new cases by the end of March 2018.

PLANS FOR 2018

The studies of the “legacy project” will be documented (including lessons learned) and presented during a workshop with all relevant stakeholders in March 2018.

In addition, NLR Nigeria successfully implemented a combined programme across thirteen states to combat tuberculosis and Multi-Drug Resistant TB, receiving funding from the Global Fund to fight AIDS, Tuberculosis, and Malaria (GFATM). This programme finished in December 2017 and an eighteen-month extension is currently discussed.

During 2017, these approaches were scaled up and specific studies were implemented, covering three states. This legacy project will run until March 2018, when results will be shared with other stakeholders in Nigeria.
NLR Mekong worked with an organisational consultant to plan and establish a new local NGO in Vietnam, to continue the programmes that are funded by external donors. Due to the uncertainty that naturally accompanies the transition phase, some key staff resigned, which led to a delay in the transition process and project activities. New staff have now come on board and the final steps in this process are expected to take place in 2018.

In 2017, many of NLR Mekong’s fundraising activities were successful, in particular securing financing for inclusive education projects, which was approved by Liliane Fonds. NLR Mekong further managed to secure support from SMHF and Peerke Donders Foundation, for continued school support for children from poor leprosy-affected families. Not only that, but also support from SMHF to continue the integrated rehabilitation projects in Kon Tum and Gia Lai. Liliane Fonds is co-funding the project in Kon Tum.

In February 2017, a really useful and beneficial training course took place in fundraising and partnerships, for NLR staff and two partner organisations. It was facilitated by the Institutional fundraiser of NLR’s International Office.

90 people were informed and educated on general disabilities to raise awareness

110 persons with disabilities were oriented on their rights – so that they can claim them

2,089 people were provided with assistive devices such as wheelchairs, crutches, sunglasses, orthopaedic footwear, and prostheses

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

5 people received vocational training to learn a trade
These Shoes are Made for Walking in Vietnam

Funded by the Dutch Postcode Lottery (NPL), NLR Mekong together with Fontys University for Applied Sciences and Liliane Fonds have established an international training course for Orthopaedic Shoe technology (OST) at the Vietnamese Training Centre for Orthopaedic Technologists (VIETCOT) in Hanoi, Vietnam.

ongoing Project in 2017

RESULTS IN 2017
• Thirty-two students from Asian countries have been trained and have graduated as Orthopaedic Shoe Technologists. Four Orthopaedic Shoe workshops have been set up in Myanmar.

LESSONS LEARNED IN 2017
• For the workshops, a number of specific machines have to be imported from the Netherlands. Unfortunately, this took longer than expected, which caused delays in setting up the workshops in Cambodia, Laos, and Vietnam.

PLANS FOR 2018
• Four more workshops will be set up in Cambodia, Laos and Vietnam in 2018.

Juma (24, student) is from Tajikstan and ended up in a wheelchair through polio. “Orthopaedic shoemaking was completely new to me. In the beginning it overwhelmed me, but now I think it’s fantastic. I want to use the experience I gain during this training to help people like me. I find it very nice to be able to do something for someone else and to be able to create something.”
Fundraising

We depend on a supportive, committed, and generous group of donors to be able to do what we do. We raise funds from private donors, but also from institutional partners. Their gifts are much, much more than just a donation. At the heart of it, our fundraising connects people who have a passion about making a difference in the world to our cause; a cause they care about.

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

PRIVATE DONORS

Thanks to the financial contribution of our private donors, we can continue to carry out our programmes on a structural basis. The income from individuals increased from €4,143,000 in 2016 to €5,866,000 in 2017 – an increase of 42%. This is great news and so encouraging, although despite this growth, the number of donors actively supporting NLR decreased from 47,186 in 2016 to 45,660 in 2017 (-3%). This is mostly due to retirement, old age, and passing away.

In order to recruit new donors, we sent out prospect mailings to people who have never given to NLR before. In addition, we also developed freestanding inserts, which went into magazines at two points during the year. In total, we welcomed 3,919 new donors. In 2018 we will be extending our donor care programme, with a greater focus on building stronger, long-term relationships with our donors. We will also be developing a dedicated programme specifically for major- and middle-sized donors.

LEGACIES

Since 2015, we have seen a noticeable decline in income from legacies. Therefore, promoting legacies was a special focus for us in 2017. We included an information leaflet in our donor newsletter about the value of legacies to our organisation. This resulted in 112 applications for our free book-shaped legacy dossier, in which a person’s wishes and practical information can be recorded. The dossier is not a substitute for drafting a will, but a valuable addition to it.

Furthermore, we participated in a joint legacy awareness campaign with a group of other Dutch NGOs, which was launched in October.

The income we received from legacies in 2017 amounted to a total of €3,275,000. This is almost twice as much as last year (mainly due to a change in regulations for annual valuing and reporting of legacies). We are extremely grateful for this resource and the impact that it has. We will be proactive in creating a legacy programme in 2018.

There are so many ways in which leprosy can change daily life for those affected. Here are just a couple of examples of why what we do is so important:

"I was born on South Sulawesi, where leprosy is endemic. I think it is terrible that people affected by leprosy are excluded from society and I would like this disease to be eradicated."

"We have always worked in the orthopaedic shoe business. People who have foot problems due to leprosy are close to our hearts."

"I find it very important that well-trained doctors and sufficient medicines are available for persons affected by leprosy."
FRIENDS OF THE NETHERLANDS LEPROSY RELIEF

Supporters nationwide have demonstrated their commitment to people affected by leprosy by organising their own fundraising activities. They are extremely valuable to us and we consider them as true ambassadors of our organisation.

COLLECTORS
In the weeks approaching World Leprosy Day 2017 (29 January), our national house-to-house collection was carried out by around 350 volunteers, which raised a total of €26,000.

LEPROSY SHOP IN DEVENTER
Volunteers at the Leprosy shop in Deventer raised €30,000 through the sale of second-hand items. We spent this resource on our self-care group projects in India.

EVENTS
Our events have a primary purpose of fundraising. At these events, we sell our range of crochet patterns and crochet packages of the famous characters of the long-running Dutch comic strip Jan, Jans en de kinderen. In 2017, we added a third pattern to our collection: Catootje. Crochet guru DenDennis designed all of the patterns out of altruistic motives. By participating in a number of events, we were able to raise awareness about leprosy and the work that we do as an organisation.

However, we have learnt that some of the visitors at these events do not really have an interest in our mission. Not only this, also the income does not outweigh the time investment. For this reason we decided to no longer participate in such events starting from 2018. We will, however, be launching a new crochet pattern that will be available in our webshop.

DUTCH MAYORS’ FOOTBALL TEAM (NBE)
The NBE played against six business clubs of Dutch Premier League Football Organisations and raised over €16,000. In honour of our fiftieth anniversary, the NBE donated an extra amount of €50,000.

LAURENTIUS SCHOOL IN BREDERDA
School pupils of grade five through to grade eight held a sponsored run and raised €24,000. It was the forty-third and last time the pupils ran to raise funds to support our work. We are very thankful to the school for being so committed and dedicated to our cause throughout the past forty-three years. Starting from 2018, they will run for a good cause that supports a disease occurring in the Netherlands and is therefore more familiar to them.
INSTITUTIONAL PARTNERS
In 2017, we received €12.3 million from fifteen institutional partners, both existing and new relations. These include The Global Fund to Fight AIDS, Tuberculosis and Malaria, the High Commissioner of Australia in South Africa, and Liliane Fonds. A huge portion of this funding came from the Dutch Postcode Lottery (NPL).

We have invested in building strategic relations and have therefore concentrated on the quality more than the quantity of proposals submitted. Our new approach proved to be successful, as the number of proposals awarded more than doubled compared to last year.

At the end of the year, we invested in our fundraising capacity with the introduction of an additional Partnerships Development Officer. In this way, we were able to step up our fundraising support to the Country Offices towards their independence and make our fundraising efforts more fruitful. In 2018, we look forward to further increasing our partnership development with other NGOs, foundations, governmental, and multilateral organisations.

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<td>Proposals pending</td>
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CONTRIBUTION BY THE DUTCH POSTCODE LOTTERY
Since 1996, we have been a beneficiary of the Dutch Postcode Lottery (NPL). We receive a fixed contribution of €1,350,000 annually, completely unearmarked, meaning we can spend this money in ways that we think best serves our mission. Because of the participants of the NPL and their generosity, we have the ability to invest in projects that are less attractive to other donors and funds, but necessary for effective leprosy control.

In addition to the annual amount, in 2017 we received an additional contribution of €9,375,000 from their “Dream Fund” for our five-year project “Stop the Transmission of Leprosy!”. With this extraordinary gift from the Dream Fund, the NPL is making new, courageous and ground-breaking projects possible.

We were invited to popular Dutch television show “Koffietijd” to explain all about our Dream Project.
Communications

We like to pass on stories from the field to our donors; those who make our work possible. Through these testimonies, everyone who supports us can understand the impact that their giving has, that it is truly changing people’s lives. At the same time, we are always looking to involve new people in our cause.

FIFTIETH ANNIVERSARY OF NLR

In 2017, we celebrated our fiftieth anniversary. To celebrate the occasion we created an awareness campaign, titled: “Stop the nerve-wracking stories about leprosy.” Personal stories from people who have been affected by leprosy were at the centre of this push. The campaign was launched in January and included a campaign website, media outlets, and a TV and radio spot.

To make our anniversary year even more memorable, in March we also held an in-depth debate at the KIT Royal Tropical Institute in Amsterdam. That afternoon we looked back at the progress and breakthroughs we have experienced over the past fifty years and looked forward. Since NLR is an ideals-driven organisation, the event also included special guests from the NGO field, who actively participated in panel discussions about sharing ideals and the important role of NGOs like NLR in developing and maintaining the wide public support for international development cooperation. Among the invitees were employees, volunteers, partner organisations, businesses, and press relations. The sons of NLR’s founders, Dick Leiker and Hans Anten, also attended the celebration.

INSPIRE & CONNECT WITH PRIVATE DONORS

Newsletter – “De Klepper”

In our donor newsletter “De Klepper,” we show our donors the impact of their support by sharing personal stories of persons affected by leprosy, case studies and factual programme highlights. In 2017, we published six editions of the newsletter.

Online & social media

Online communication and promotion are becoming increasingly significant. It not only offers opportunities for interaction but provides extra visibility as an organisation. As far as social media is concerned, at the moment we are active primarily on Facebook and Twitter. Both channels provide more traffic to our website. Using posts on social media, we can support ongoing campaigns.

APPRECIATION INCREASES (CHARI-BAROMETER)

THE APPRECIATION FOR NLR INCREASED FROM 51 POINTS TO 55

IN THE RANKING “IMAGE” WE MOVED UP 3 POSITIONS FROM 77TH TO 74TH PLACE

THE AWARENESS OF NLR HAS DECREASED FROM 30 POINTS TO 25
HANDLING OF COMPLAINTS
At NLR, we take complaints very seriously and do our utmost to handle them in a satisfactory manner. Any complaints are recorded in our register, in accordance with the procedural requirements of ISO 9001:2015. This registration took effect on 1 September 2017. As of that date, we accurately registered twenty-one complaints. We estimate that we received and handled sixty complaints before that date. Most complaints were about the frequency and costs of our direct mail. We made sure that those who did file a complaint were satisfied with how it was handled.

MEDIA
Raising awareness for leprosy and our work remains crucial. We do this, among other things, by generating free publicity as much as we can.

In 2017, we managed to have NLR content published in Dutch newspapers and magazines six times, in Vice Versa, Adformatie, Nederlands Dagblad, Max Magazine, and De Telegraaf.

On World Leprosy Day (29th January), Radio 1 broadcasted the radio documentary “Een tijd van daarvoor en een tijd van daarna,” which tells the life story of Dr Dick Leiker, one of the founders of NLR. His journey of dedication as a leprologist and personal drama leaves no one untouched. After winning funding from the Dutch National Postcode Lottery’s Dream Fund, we were invited to popular Dutch television show “Koffietijd” to discuss our innovative project “Stop the Transmission of Leprosy!”.

During the second episode of a new TV programme called “Wie maakt het verschil?” of Dutch broadcaster MAX (on channel NPO2), NLR ambassador Andrea Kruis was shown paying a visit to one of the leprosy colonies that we support in India. During this impressive journey, Andrea was accompanied by Charles Phaff, the leprosy doctor who also accompanied her father and famous cartoonist Jan Kruis on his journey through Mozambique in the year 2001.

AMBASSADORS
Ambassadors play such an important role for NLR. Not only are they a role model to the Dutch public – they have also seen our work in the field with their own eyes. They help us increase awareness of our organisation by volunteering in campaigns and events and by promoting NLR within their own network.

Andrea Kruis followed in the footsteps of her father and cartoonist Jan Kruis. He passed away on 19 January 2017. Jan Kruis was an invaluable ambassador of NLR for over fifteen years, we will forever be grateful for the difference he made. Andrea travelled to India to shoot Dutch TV show “Wie maakt het verschil?”. In 2018, she will be making an animation about leprosy and our work, starring best friends Fransje and Marie from “Vijftien en een half,” the Dutch cartoon series drawn by Andrea herself.

Our latest TV and radio spot featured a voice-over from Huub Stapel. In 2018 he will pay a field visit to India. Curt Fortin was present at the forty-third sponsored run to raise funding for NLR, organised by the Laurentius School in Breda. Crochet guru Den Dennis designed a new crochet pattern for the cartoon character “Catootje.” In 2018, he will be designing a fourth pattern.

Ambassador Andrea Kruis:
"My father described leprosy as an affront to human dignity. And there is not much that I want to add to this. NLR helps people who help people affected by leprosy. That is all that matters. During my field visit to India I have seen with my own eyes how these wonderful people make a meaningful difference for those who are affected by leprosy. They put their heart and soul into everything they do to help them."
A solid structure of our organisation naturally provides opportunities to enhance efficiency and effectiveness. Solidity as opposed to rigidity. Because of the high pace of change in the world today, new insights and discoveries require a readiness to make changes wherever and whenever necessary. This is what enables us to serve those in need effectively, responsibly, and in a sustainable way.

Our staff

STAFF COMPOSITION
NLR’s International Office is based in Amsterdam, the Netherlands. The staff in that location is comprised of 27 employees (22.8 FTE), working across four departments. The management and execution of field activities in 2017 were delegated to five professional Country Offices in Mozambique, India, Indonesia, Nepal and Brazil, with a total of 121 employees. In two Country Offices, in Nigeria and the Mekong Region, with a total of 22 employees, NLR began phasing out its funding towards 2018.

EMPLOYEE REPRESENTATIVE BODY (PVT)
The PVT is entitled to advise the Executive Director on planned changes in the organisation, labour conditions, and terms of employment that affect more than 25% of the staff at the International Office.

In 2017, the PVT finalised its active involvement in advising on the consequences of planned budget reductions due to a decline in revenues from legacies that would affect employment and terms of employment. The working groups (through which staff could advise in a co-creation process on a number of aspects of NLR’s daily practices and policies) delivered advice on how to save on expenses and how to increase trust and confidence of management staff, who are often required to make critical decisions under very challenging circumstances. The overall effectiveness of internal communications has been improved.

After receiving the final “non-negative” advice from the PVT on the budget reductions and related measures, our Executive Director decided not to implement the planned measures that affect the staff’s terms of employment. The above budget income figures in 2017 provided the necessary financial room to do so.
GOVERNANCE AND SUPERVISION

Supervisory Board
At NLR, the Supervisory Board is our highest body. It oversees the Executive Director’s performance, as well as policy and general affairs. The Executive Director is responsible for managing the organisation, under the guidance of the Supervisory Board. In the bylaws, the division of responsibilities between supervision and management is worked out in full detail.

Members of the Supervisory Board and their functions
In 2017, the Supervisory Board consisted of the following members:

A. van Ojik - Chairman
> Special Envoy for Migration, Dutch Ministry of Foreign Affairs (until March 2017)
> Member of the Second Chamber of the Dutch Parliament of the Green Left party GroenLinks

P.R. Klatser - Vice-Chairman
> Strategic Lead Prevention Markers, Janssen Prevention Center, Leiden.
> Professor of Development and Evaluation of Diagnostic Tests in Developing Countries, University of Amsterdam.
> Extraordinary Professor of Biomedical Research for Development, Vrije Universiteit Amsterdam.
> Chair, Q.M. Gastmann Wichers Foundation.
> Secretary/treasurer, Eijkman Medal Fund Foundation.

R.L.J. Greveling - Chair Financial Audit Committee
> Director of Finance, Stichting Koninklijke Visio.

Mrs D.M.P.J. Go-Feij
> Director and Owner, Caraz Consultancy.
> Member Exam Committee Management Studies, NCOI.
> Board Member, Eden Soestdijk Foundation.
> Visiting Lecturer Fundraising, Grant making & Sponsoring, Hogeschool Windesheim.

M.R.A. van Cleef
> Board member, Eijkman Medal Foundation.
> Membership International Union Against TB and Lung Disease.
> Membership American Thoracic Society.

J. van Berkel - Director - NLR
> President of ILEP, International Federation of Anti-Lepery Associations.
> Chair of the Board of Directors, Goede Doelen Nederland (Dutch branch organisation for charities).
> Director/Chair Executive Group LRI, Leprosy Research Initiative.
> Member of the Board of Directors, Dutch Coalition for Disability and Development (DCDD). 
> Member of the Board of Directors, Steunfonds.
> Member of the Nederlandse Händelvereniging.

The Dutch Act on Management and Supervision (Wet Bestuur en Toezicht) stipulates that a certain gender diversity is required on the Supervisory Board. At least 30% of the seats are required to be occupied by women or at least 30% of the seats by men. In 2017, our Supervisory Board met these criteria; with the ratio of two female members to four male members. None of their positions pose any conflict of interest with the functions of the Supervisory Board or the Directorate of NLR.
Upon their annual visit to the office and meetings with the staff of NLR in September 2017, the Supervisory Board collected additional information and insights about the culture and activities at the International Office. This supplemented the information already provided by the Executive Director.

Every year, the Supervisory Board evaluates its own functioning. The 2017 evaluation was supported by an external consultant. The outcome was discussed at a board meeting in December 2017. The Board concluded that it has access to sufficient information to supervise the Executive Director. The Board planned the agenda for its 2018 meetings.

The Supervisory Board met six times in 2017. Besides the regular quarterly meeting, two special meetings were held. The first was to discuss the preconditions for a transfer of governance, regarding the Country Office in Brazil to a newly formed local board. At the second special meeting, the Board of Supervisors were informed about trends in the Dutch fundraising market and discussed the NLR Fundraising Policy, as well as the Development of the Key Priority Programmes.

The Supervisory Board also evaluated the Executive Director’s performance and the cooperation between the Board and the Executive Director.

**DIRECTOR’S REMUNERATION**

The Supervisory Board is responsible for determining the remuneration policy and the Executive Director’s salary. NLR follows the Regulation for the Remuneration of Directors of Charities, in Dutch Regeling beloning directeuren van goede doelen (van Goede Doelen Nederland). The position as director of NLR is more than a full-time job. It is a role with great responsibilities and demands high professional performance.

Ultimately, the director is responsible for the results of an international organisation that receives over €10,000,000 per year, where some 170 people work, which receives the support of approximately 45,660 donors, and has 350 volunteers. An organisation also, that cooperates with many partners, including health ministries, scientists, companies, and other NGOs. Compared to positions with a comparable complexity and responsibility, the Supervisory Board considers the current remuneration of the director fair and reasonable.

The remuneration is reviewed every three years. The most recent update took place in 2017. The Board concluded that the remuneration policy was performed in accordance with regulations. The 2017 annual salary of the Executive Director Mr Jan van Berkel was €114,038 (1 FTE/12 months). Van Berkel donated his remuneration of €5,000 as chair of Goede Doelen Nederland to NLR. For further details, see page 23 of the Annual Accounts of NLR.
Learning organisation

NLR2020
In order to be able to better relate to our local context and to raise funds in the countries in which we are working, we have designed the NLR2020 project; a project that aims to transform our offices into local organisations that will keep on working together as part of an NLR Alliance.

In 2017, we continued the process of strengthening our offices in the fields of programme management and fundraising. Staff were hired and training was conducted. We saw successful fundraising in Indonesia and Mozambique. We also hired three new Country Directors (Indonesia, Brazil, and Mozambique) in 2017, to lead those offices into the future. In Brazil, we have selected Board Members, who will start operating as soon as the local organisation is officially created. This process may take a while as it has slowed down since it was agreed that the Brazil Office was not yet ready to take that step.

In addition to establishing local organisations, NLR will also set up an Alliance in which the organisations will be collaborating, along with the International Office. The establishment of the four new Key Priority Programmes (KPPs) is a significant first step towards more joint learning, cooperation, and working together to achieve one shared goal. Once this method of working together is fully figured out and functioning effectively, the Alliance can be fully established.

RISK ANALYSIS & CONTROL
From the annual risk analysis that all NLR offices make, shortage of revenues is still the largest threat to the continuity of NLR operations. Training in Institutional Fundraising is aimed at acquiring a more diverse range of income sources for our Regional Offices. Intensive support in training, donor mapping, proposal writing, and actual applications for funding continues to be provided by the International Office. A decrease in income from legacies is taken into account in the overall NLR budgets projections. Another risk relates to new regulations. Specifically the European Union General Data Protection Regulation (GDPR) requires specific attention.

CERTIFICATION OF ISO
In 2016, we began preparations for ISO certification. This involved updating existing and developing additional procedures and organising internal audits to verify the use of these procedures. After an audit by an external agency, the International Office received the ISO 9001:2015 and the branch-specific ISO 9001:2015 Partos certifications.

SOCIAL RESPONSIBILITY (MVO)
NLR operates on a carbon-neutral basis. In 2017, the CO2 emissions due to air travel and printing were compensated by contributions to sustainable energy projects. In accordance with the guideline “Financial Management of Fundraising Institutions,” issued by Goede Doelen Nederland, our starting point in the management of our reserve funds is the preservation of our capital. We invest our reserve funds exclusively in investment products offered by governments and companies that respect human rights, reject child labour, and manage their operation in a sustainable fashion.
Partners & collaborations

NLR is a relatively small player in the field of international development aid. To keep the fight against leprosy high on the agenda, collaboration is vital.

NLR is an active member of the International Federation of Anti-Leprosy Associations (ILEP). Our Executive Director is President of ILEP and we actively contribute to the ILEP Technical Committee. NLR cooperates in the ILEP Triple Zero campaign: Zero Transmission, Zero Disability, Zero Discrimination. We presented our KPP3 programme as an example in the joint learning process with other ILEP members. ILEP members also actively cooperate with us in LPER, PEP++ and in the Leprosy Research Initiative (LRI). In addition, we work closely with the World Health Organization (WHO) and the Neglected Tropical Disease Non-Governmental Development Organization Network (NNN). The appointment by the United Nations of Ms Alice Cruz, as a Special Rapporteur on eliminating discrimination of persons affected by leprosy and their family members, was a big success in the fight to get leprosy-related exclusion higher on the agenda of governments worldwide.

As an active member of the Dutch Coalition on Disability and Development (DCDD) in the Netherlands, we contribute to the lobby of the Netherlands government for implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Our collaboration with Liliane Fonds included the first full year of cooperation in Indonesia, where NLR is managing their programme and works towards achieving efficiency and synergy in our work by combining projects and support work in the field of disability and inclusion.

In addition, we were happy to continue our cooperation with long-term funding partners, such as the Dutch Postcode Lottery, the Global Fund to Fight AIDS, Tuberculosis and Malaria, Achmea Foundation, Novartis Foundation, Sasakawa Memorial Health Foundation, Peerke Donders Stichting, Fondation Mérieux and our ILEP partners such as Lepra UK and effect:hope, who are also funding programmes that are carried out by NLR Offices in Mozambique and Indonesia.

THANKS TO...

We would like to give a massive thank you to everyone that partnered with NLR in 2017.

Achmea Foundation, AIFO, American Leprosy Missions, ARFH, CBM, CIOMAL, DAHW, Damien Foundation, DCDD, Disability Studies in Nederland, Dutch National Postcode Lottery, effect:hope, Embassy of the Kingdom of the Netherlands in Indonesia, Enablenet, Erasmus Medical Centre, FAIRMED, Fondation Mérieux, Fontilles, Fontys, Fondation Raoul Follereau, The Global Fund to Fight AIDS, Tuberculosis and Malaria, Achmea Foundation, Novartis Foundation, Sasakawa Memorial Health Foundation, Peerke Donders Stichting, Fondation Mérieux and our ILEP partners such as Lepra UK and effect:hope, who are also funding programmes that are carried out by NLR Offices in Mozambique and Indonesia.
**Finances**

**2017 RESULT IN SHORT**

The annual accounts are a consolidation of NLR’s annual accounts and the annual accounts of the Leprosy Research Initiative (LRI). The NLR 2017 budget is a balanced one. In the annual accounts, however, the budget for 2017 ends with a deficit of €121,000, due to the fact that LRI budgeted a deficit for 2017.

The received income from the Dutch Postcode Lottery (NPL) of €9.38 from the NPL’s Dream Fund for the NLR Project “Stop the transmission of Leprosy” had a significant impact on the total income for 2017. Though this total income is reflected in the income for 2017, it is to be spent during the five year implementation period of the project.

The 2017 total consolidated income was €20.9 million (2016: €10.4 million), while €12.6 million was budgeted. Total expenses were €11.3 million (2016: €11.5 million), while €12.8 million was budgeted.

The overall result for 2017 is €9.7 million (2016: a loss of €914,000), while a deficit of €121,000 was budgeted. After adding earmarked funds to the earmarked reserves, the net surplus for 2017 would be €2.2 million.

**2017 FINANCIAL HIGHLIGHTS: INCOME**

**NPL Dream Fund**

Besides the annual contribution of €1.35 million that we receive as a beneficiary of the Dutch Postcode Lottery (NPL), in 2017 an amount of €9.38 million was awarded by NPL’s Dream Fund for the NLR Project “Stop the transmission of Leprosy.” The total amount for this five-year project was received in 2017 and has been taken as income in 2017. This decision, of course, has a significant impact on the presented income in 2017. The amount that was not spent in 2017 is maintained as an earmarked fund for future financing of the project.

**Legacies**

In the 2017 budget, we decided to decrease the forecasted income from legacies, from the €2.5 million that was projected in earlier years, to €1.8 million in 2017. This decision was taken following a decrease in income from legacies for two subsequent years. Once again, income from legacies proved extremely difficult to predict. In 2017, the income from legacies was €3.28 million – much higher than expected. About 50% of the amount by which we exceeded our budget was explained by the simple fact that it was a good year; the other half was explained by a change in regulations for annual valuing and reporting of legacies, caused by an amendment of Guideline 650 (Dutch: Richtlijn 650) for the Annual Reporting of fundraising charities in the Netherlands.

**Dutch Ministry of Foreign Affairs**

In 2017, under the Accountability Fund an amount of €108,900 was received from the Dutch Ministry of Foreign Trade and Development Cooperation for the LEAP programme: Local Economic development of people with disability through active Advocacy for an inclusive Policy. As the project activities and expenses will start in 2018, this amount was carried over to 2018.

**Fundraising in the Netherlands**

In the 2017 budget, we anticipated that income resulting from our own fundraising (excluding income from legacies) would remain constant. This income flowing from donations by individuals, companies, and the return of goods and services was (not including legacies) budgeted at €2.5 million; actual income, however, amounted to over €2.64 million.
2017 FINANCIAL HIGHLIGHTS: EXPENSES

Field programmes
Direct expenses for field programmes amounted to €6.2 million (2016: €6.8 million). A budget of €5.7 million was projected.

Expenses on the GFATM (Global Fund to Fight AIDS, Tuberculosis, and Malaria), TB, and MDR TB activities in Nigeria proved lower than budgeted. The exact amount was not yet clear at the moment of approving NLR’s 2017 budget.

Other expenses were higher (€4.3 million) than budgeted (€2.2 million), as funds provided by other donors could cover these expenses. Also included are expenses that were financed as investments flowing from our reserves.

Supporting projects
The expenses made for supporting projects (€480,000) were lower than budgeted (€921,000). In 2017, the budgets for Key Priority Programmes and technical capacity building have not been entirely exhausted, as both activities were still being prepared in 2017.

Research
The research expenses include research funded by LRI, expenses made for the LPEP project, and the NPL-funded project “Stop the Transmission of Leprosy.” The latter project was not budgeted; expenses on research, therefore, amounted to €1.5 million while they were budgeted at €1 million.

NLR 2020
In 2017, we spent an amount of €436,000 on the NLR 2020 programme from our earmarked investment reserve. The programme transforms our branch offices into local NGOs embedded in their local contexts.

Other expenses flowing from reserves
Other expenses flowing from our investment reserves, amounting to €714,000 in total, include investments connected to our 50th anniversary and investments in so-called Priority Areas, which promote a more theme-based focus within our field programmes. In addition, the implementation of a financial administrative package for all Country Offices and the ISO 9001 certification are included.

We also invested in the transition plans for our Nigeria and Mekong offices, after we decided to end their structural funding while continuing to assist in their ongoing programmes, based on external funding, and transitioning into local NGOs.

Expenses drawn from earmarked funds
We spent a total amount of €377,000 on the NPL-funded project “These shoes are made for walking.” On the five-year, NPL-funded project “Stop the Transmission of Leprosy,” we spent an amount of €537,500 in 2017.

Information and awareness raising
Total expenses on information and awareness-raising activities added up to €715,000, while €513,000 was budgeted. These additional expenses were made in light of our 50th anniversary and were financed from our reserves to the extent that they could not be covered by a reduction of expenses on fundraising.

Fundraising
Expenditure on fundraising was €679,000, instead of the budgeted €787,000. We intentionally lowered our spending in this field to offset additional expenses made for information and awareness raising. Total spending on our own fundraising in relation to the total raised income, amounted to 3.3%. This low percentage is for the most significant part explained by a high income in 2017, incurred by the receipt of the NPL funding for the project “Stop the Transmission of Leprosy.”

Though the terminology “income from own fundraising” no longer appears in Guideline 650 (Dutch: Richtlijn 650) for the Annual Reporting of fundraising charities in the Netherlands, this percentage would have been 11.5%, while 15.7% was budgeted. This is well under the maximum of 25% set by the Dutch Central Bureau for Fundraising. NLR strives to keep the costs of its own fundraising under 21% of the income it raises. This lower percentage is achieved by a high income from legacies. In 2016, the percentage was 18.8%.
OTHER POINTS OF INTEREST

Consolidated annual account
The Leprosy Research Initiative (LRI) was registered as a Foundation under Dutch law on 1 June 2015. LRI is a unique model of cooperation and coordination in the funding of research. In 2015, five NGOs, i.e. American Leprosy Missions (ALM), the German Leprosy Relief Association (GLRA), effect:hope, The Leprosy Mission International (TLMI), and the Netherlands Leprosy Relief (NLR), jointly committed to the fight against leprosy and combined their funding for leprosy-related research in the LRI fund. The management of the Foundation is in the hands of NLR director Jan van Berkel, who implements the decisions of LRI’s Executive Group and is supervised by NLR’s Supervisory Board. Therefore, LRI’s annual accounts for the year 2017 have been consolidated with NLR’s 2017 annual accounts. In the consolidated annual accounts, the independent LRI annual accounts are included, with an explanation where the consolidated annual accounts differ from NLR’s annual accounts.

Financial income and expenses
The balance of financial income and expenses regarding invested reserves was €75,000 in total, which is slightly below the budgeted amount of €80,000. The 2016 result was somewhat higher: €107,000. An external agency manages our current portfolio. Investments must be in line with NLR’s investment policy, which prescribes investments in sustainable, socially responsible, and low-risk bonds. Adherence of the investment manager to this policy is verified twice a year. In 2017, the yield on our portfolio was 0.3% (2016: 1.8%).

Reserves and funds
NLR’s reserve policy is closely linked to its long-term relationships with numerous partners in endemic countries. Our partners must be able to rely on NLR and be sure that it can fulfill its commitments. For this reason, we have an earmarked reserve for specific projects that in 2018 will be approved by the Supervisory Board. Our project reserve amounts to €5.0 million.

Looking beyond 2017
The continuity reserve is an earmarked reserve that covers the organisation’s own continuity risks. According to CBF guidelines, this reserve may amount to a maximum of 1.5 times an organisation’s annual costs. NLR aims at a continuity reserve of between 0.5 and 1 times the work organisation’s annual costs. At the end of 2017, the continuity reserve held €3.8 million (1.3 times the work organisation’s annual costs). Another earmarked reserve is the investment reserve, which contains funds approved for internal investment in innovation and capacity building, a biennial Priority Areas project, and transition budgets for our Country Offices in Nigeria and the Mekong Region. At the end of 2017, these earmarked investment reserves totalled €1.7 million.

Finally, there are two earmarked funds for the NPL-funded projects “These shoes are made for walking” and “Stop the transmission of Leprosy.” At the end of 2017, these funds held a combined total of €9 million.
**NLR BUDGET 2018** Amounts x €1,000

This is the approved 2018 NLR budget, compared to NLR’s 2017 realisation and budget. For the independent 2018 LRI budget, please refer to the 2017 LRI annual accounts.

**INCOME:**

- Income from individuals 3,860
- Income from companies 30
- Income from lotteries 1,350
- Grants from governments 114
- Income from allied and joint non-profit organisations 0
- Income from other non-profit organisations 3,968

**Sum of the raised income** 9,322

- Income in return of goods and services 10
- Other income 99

**Total income** 9,431

**EXPENSES:**

- Leprosy control and disability programme activities 6,356
- Coordination and medical advice 1,403
- Information and awareness raising 522

**Total expenses** 9,578

Financial income and expenses 147

**Balance of income and expenses** 0

The projections for 2019 and 2020, linked to the rolling Multi-Annual Strategy, are for the most part kept equal to the 2018 budget, except for income from legacies. We expect that income from legacies will further decline in 2018 and 2019, to €1 million in 2019. In 2020 we expect the income from legacies to reflect 2019, i.e. €1 million.