



# LEPROSY RESEARCH INITIATIVE



**Annual Report 2020**

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## 1. Introduction

This is the sixth Annual Report of the Leprosy Research Initiative (LRI). The LRI, founded in 2013, is a unique model of cooperation and coordination of international NGOs who combine their funding for research in a joint fund under one policy. Through this partnership we can promote efficiency and quality in leprosy research, increase the participation of researchers from endemic countries and stimulate the engagement with persons affected by leprosy.

The LRI is a foundation under Dutch law and is managed by the Director of NLR, implementing the decisions of the LRI Executives Group and supervised by the Supervisory Board of NLR. This annual report gives account to the LRI partners and other stakeholders of the LRI proceedings and activities in 2020. The financial proceedings have been audited by an independent auditor.

In 2020 the LRI allocated €1.3 million to 29 research projects. Included in this amount is a contribution of €295,000 by the Turing Foundation as co-financier of the LRI.

We have witnessed major impact of the COVID-19 pandemic around the world in all areas of society. One of the first implications for our work was that we had to cancel the annual Spring Meeting. Not surprisingly, the research projects funded by the LRI have also seen disruptions in their work which are highlighted in this annual report. At the same time, in spite of the pandemic, some projects were able to continue or commence their work by adapting their plans to the situation. We commend all the teams for their commitment and resilience in this challenging year and we look forward positively and confident that in 2021 the impact of COVID-19 on our daily work and life will gradually decline and we can focus our attention again on our road towards zero leprosy.

This year we unfortunately had to say goodbye to one of our founding partners effect:hope – who withdrew their contribution to the LRI, partly as a consequence of the financial impact of the COVID-19 pandemic. We are grateful for the years that we have joined forces and we hope that in the years ahead there will be other opportunities to partner with them.

We also welcomed new partners to the LRI: Anesvad Foundation is a Spanish NGO that works to control, eliminate and eradicate skin-related Neglected Tropical Diseases (skin NTDs) in Sub-Saharan Africa with integrated approaches. It is our pleasure to work with Anesvad Foundation as a full partner.

We are also pleased to have welcomed our new associate partner, St Francis Leprosy Guild. St Francis Leprosy Guild is a UK charity that has been supporting the fight against leprosy for 125 years. Last but not least: Damien Foundation was already one of our associate partners but decided to become a full partner as of 2020.

The current partners working together in the LRI and constituting the LRI Executive Group are:

- American Leprosy Missions (ALM)
- German Leprosy Relief Association (GLRA)
- The Leprosy Mission International (TLMI)
- NLR
- Damien Foundation
- Anesvad Foundation

Upon joining, LRI partners commit to support the LRI for a period of three years. At the end of each year partners decide about an extension of their commitment with one year in order to maintain a three year funding horizon.. In 2020, the partners have therefore extended their commitments until the end of 2022.

In December 2020, Jan van Berkel retired and Linda Hummel became the new Director of the NLR and Chair of the LRI Executive Group. Jan van

Berkel has been one of the initiators of the LRI and an important driving force. We are highly appreciative for his strategic vision and leadership. We look forward to working with Linda Hummel in this new role.

We are grateful to the many outstanding professionals and experts that contribute to the LRI Steering Committee and the Scientific Review Committee and to the independent external reviewers, on whom we depend to ensure a rigorous and peer-reviewed selection process, a cornerstones of our work.

The LRI is keen to welcome new partners and co-financiers in its exciting model of research funding that offers perspectives for innovation and for increasing effectiveness in research that contributes to the goal of zero leprosy.

We wish to thank everyone who contributed to the LRI work in 2020 via personal involvement, financial support or co-operation.

Linda Hummel	Bram van Ojik
Director of NLR	Chair Supervisory Board

## 2 Vision, mission and priorities

### Vision

A world free from leprosy

### Mission

To contribute to our vision by:

1. promoting, facilitating and funding high-quality leprosy research;
2. strengthening research capacity in endemic countries, and;
3. facilitating translation of research results into policy and practice.

### Purpose

- To establish and maintain a joint research fund to support leprosy research that fits with the LRI priorities.
- To secure funding from external sources for research projects related to the LRI joint research agenda that cannot be funded (solely) by the LRI fund.

### Objectives

- To facilitate the development of research funding proposals in collaboration with concerned research groups.
- To establish and maintain a joint research fund for leprosy research.
- To facilitate adequate resourcing of leprosy research projects.
- To provide an efficient, transparent and scientifically rigorous selection process of research proposals that fit the priorities set in the joint research policy.
- To provide a scientifically high-quality monitoring mechanism of research projects supported by the LRI.
- To expand the number of partners in the LRI.

### Current research priorities

Based on current global research needs, the partners of the LRI have agreed on a joint policy with clearly defined research priorities. Research results should be directly applicable to leprosy services or to the wellbeing of persons affected by leprosy. In addition research projects need to generate results that can be used in the short- or medium term.

The five research priority areas as defined at the launch of the LRI and still applicable to the the 2020 call for proposals:

#### 1. Early detection

### Promote and enable early detection of leprosy

Early detection is important to reduce further transmission, but particularly because it reduces the risk of permanent impairments. The LRI will support studies that examine approaches, methods or tools to improve early case detection. This will include health systems approaches to promote community awareness, appropriate health-seeking behaviour of patients and access to services, as well as the testing of lab-based tools for subclinical infection or disease. It may also include interventions to reduce community stigma, if this is a barrier to early detection in a given setting.

## 2. Nerve function impairment and reactions

### **Promote prevention, early detection and effective treatment of nerve function impairment (NFI) and reactions**

Neural and ocular impairments are the main causes behind the many problems persons affected by leprosy may experience. The LRI will therefore support studies of approaches and interventions for primary prevention of nerve or ocular damage, methods to improve detection and interventions and treatment regimens to improve the prognosis of NFI and leprosy reactions.

## 3. Inclusion

### **Promote inclusion of persons affected by leprosy in society**

Exclusion from society is the most feared and severe consequence of leprosy. This may happen overtly, as when people are sent away from their home or face divorce, or in much more subtle ways, such as loss of status, gossip, avoidance, etc. The LRI will support research that promotes inclusion and participation of persons affected by leprosy in any aspect of society. Important aspects are relationships, including marriage and promotion of sexual and reproductive health and the rights of affected persons, livelihoods and labour participation, education, and participation in civil organisations, such as disabled people's organisations. Participation of affected persons in leprosy services is another aspect that deserves specific attention.

## 4. Prevention of disability

### **Improve the coverage of prevention of disability activities and their integration in national programmes and integrated wound and limb care programmes**

Prevention of disabilities (POD) is a core component of leprosy services. Appropriate methods and tools are already available, but often they are not used and not used adequately. Examples are nerve function assessment and self-care training. Usually, POD interventions or activities are carried out in a leprosy-only mode, while there are many people with similar problems who would also benefit from such interventions and activities (e.g. people with diabetic neuropathy). The LRI will support implementation research that explores or provides ways to improve the use of existing methods and tools for POD. In addition research that explores the integration of POD interventions in national leprosy policies and programmes, and the integration of leprosy-related POD in general wound and limb care programmes.

## 5. Interrupt transmission

### **Test methods and tools to interrupt the transmission and incidence of leprosy, including increasing the coverage of effective contact management and chemoprophylaxis**

The ultimate goal of leprosy control services is to interrupt the transmission of leprosy. Current approaches to case detection and treatment with MDT have not led to a sufficient decrease in incidence of leprosy in many countries or areas within countries. Recent research has shown that strategies aimed at contacts of leprosy patients are the most promising and cost-effective options to further reduce the incidence of leprosy. The LRI will support implementation research aimed at introducing or scaling up effective contact management and chemoprophylaxis interventions. Testing of additional contact examination interventions, chemoprophylaxis regimens or other prophylaxis approaches, such as immune-prophylaxis, would be eligible for support. Studies aimed at reducing or removing barriers to the effective use of contact-based interventions are also eligible for support.

### 3 Impact of COVID-19 pandemic

We have witnessed a major impact of the COVID-19 pandemic around the world in all areas of society. One of the first implications for our work was that we had to cancel the annual Spring Meeting. Not surprisingly, the research projects funded by the LRI have also seen disruptions in their work due to lockdown situations with staff unable to travel to work, patients and persons affected by leprosy unable to visit the clinic or research sites and community health workers unable to conduct home visits. In some cases staff was asked to work on COVID-19 related assignments instead of their regular work. We have received very sad news from one of the research teams that reported to have lost a member of staff due to COVID-19.

No-cost extensions have been requested and approved by the Scientific Review Committee to support the projects that have been impacted by the COVID-19 pandemic.

At the same time, in spite of the pandemic there are also projects that were able to continue or commence their work sometimes by adapting their plans to the situation.

We commend all the teams for their commitment and resilience in this challenging year and we look forward positively and confident that in 2021 the impact of COVID-19 on our daily work and life will gradually decline and we can focus our attention again on our road towards zero leprosy.

Chapter 5 reports on how the COVID-19 pandemic has impacted our capacity building activities.

## 4 Research

### 4.1 Proposals received and approved

The LRI uses a two-stage call for proposals. Initially applicants submit a Letter of Intent (LoI). These LoIs are reviewed by the LRI Steering Committee (SC) using the following criteria:

1. relevance and quality;
2. potential impact;
3. involvement of researchers from endemic countries and persons affected;
4. value for money.

Successful applicants are invited to further develop their research idea into a full proposal. The full proposals are reviewed by (at least) two independent external reviewers using the following criteria:

1. scientific quality and importance;
2. impact;
3. requested support.

Following their review, applicants are invited to respond to the feedback given and submit a rebuttal proposal. This rebuttal is reviewed by the independent Scientific Review

Committee (SRC). Using the same criteria as the external reviewers, the SRC advises the Executives Group (EG) on the scientific merit of the protocols. The SC further reviews the full proposals with the main aim of advising the EG with regard to perceived priority. When there are too many scientifically meritorious protocols, the SC will rank the protocols according to their priority. Finally, the EG decides which proposals are accepted for funding, taking into account the available budget.

For the 2020 call for proposals, the success rate of the first stage (LoI selection) was 31% – 16 of the 52 applicants who submitted an LoI were invited to submit a full proposal (Table 1). One applicant did not submit a full proposal and therefore 15 full proposals were received. Seven full proposals were accepted for funding, two projects focusing on inclusion, three on strategies and tools to interrupt transmission, one on nerve function impairment and reactions and one on prevention of disabilities (Figure 1).

**Table 1: Success rate in budget years 2016-2020**

Budget year	Selection of Letter of Intent (LoI)			Selection of Full Proposals (FP)		
	Number	Accepted	Success rate	Number*	Accepted	Success rate
2016	70	15	21%	16	11	69%
2017	40	6	15%	10	4	40%
2018	58	21	36%	20	10	50%
2019	56	20	36%	24	5	21%
2020	52	16	31%	15	7	47%

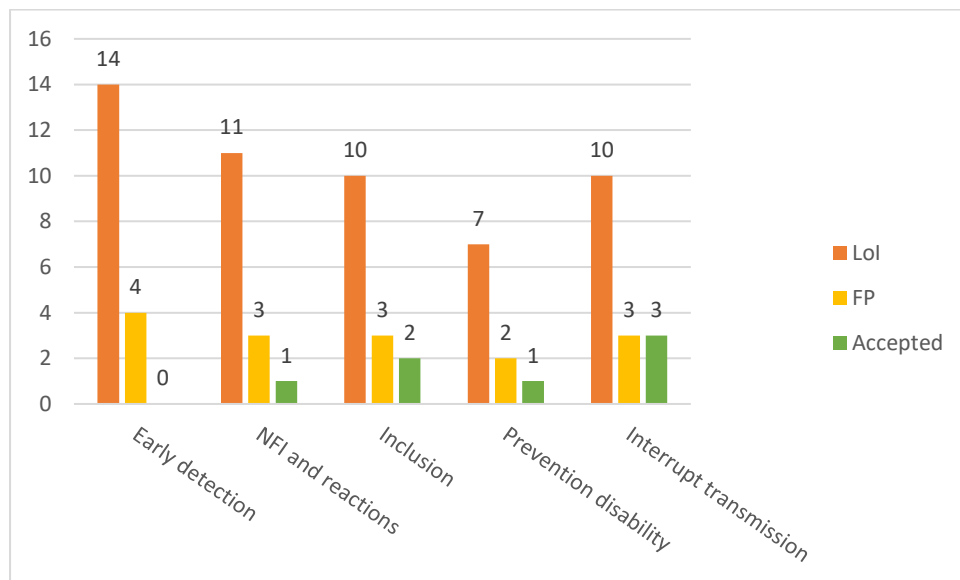
*\*In 2016, one applicant from the preceding budget round was invited to skip the LoI phase and re-submit his full proposal in 2016. Similarly, in 2017 four applicants skipped the LoI phase. In 2018, one applicant successfully obtained funding elsewhere and did not submit a full proposal. In 2019, six projects from the previous budget round were invited to submit a revised full proposal, of which four submitted one. In 2020 one applicant did not submit a full proposal.*



Looking at the origin of the main applicants, over 80% of applicants submitting an Lol originated from, or worked in an endemic

country. This was similar among applicants submitting a full proposal (Table 2).

**Figure 1: Number of Letters of Intent and full proposals by research priority in 2020**



NFI: nerve function impairment

**Table 2: Applications by origin of lead applicant**

Priority	Letter of Intent		Full Proposals	
	Endemic	Non-endemic	Endemic	Non-endemic
1. Early detection	12	2	3	1
2. Nerve function impairment and reactions	9	2	2	1
3. Inclusion	7	3	2	1
4. Prevention of disability	7		2	
5. Strategies and tools to interrupt transmission	9	1	3	
Total	44	8	12	3

## 4.2 New research projects funded

**Table 2: New projects accepted for funding in budget round 2020**

Research priority	Title Research Project	Lead applicant	Total grant	Focus country
2	Efficacy and Tolerability of Adjunct Metformin in Combination with Standard Multidrug Treatment for Multibacillary Leprosy: A Randomized Double-blind, Controlled Proof-of-Concept Trial in Indonesia	Dr Marlous Grijzen <i>University of Oxford, UK (based in Indonesia)</i>	€199,946	Indonesia
3	Improving mental health and quality of life of persons affected by leprosy or Buruli ulcer in Southern Nigeria	Dr Ngozi Ekeke <i>German Leprosy and TB Relief Association, Nigeria</i>	€199,933	Nigeria
3	Capturing culture-specific stigma dynamics by understanding ‘What matters most’ to inform (generic) measures to assess and approaches to reduce stigma: a three-country study	Dr Ruth Peters <i>VU University Amsterdam the Netherlands</i>	€269,256	Indonesia, India, Nigeria
4	Assessing the effectiveness of family-based approaches aimed at prevention and sustainable self-management of disabilities, impacting the quality of life, mental wellbeing and participation of people with leprosy, podoconiosis and lymphatic filariasis and their families in the Amhara region, Ethiopia	Mr Moges Wubie <i>Ethiopian National Association of People Affected by Leprosy (ENAPAL), Ethiopia</i>	€203,209	Ethiopia
5	Molecular Mechanisms of Immunomodulation Imparted by Mycobacterium indicus pranii (MIP) Against Multibacillary Leprosy	Dr Pushpendra Singh <i>ICMR-National Institute of Research in Tribal Health, India</i>	€199,390	India
5	Leprosy Antimicrobial Resistance Surveillance in Post Exposure Prophylaxis Setting in Tanzania (LARS)*	Dr John Changalucha <i>National Institute of Medical Research (NIMR), Tanzania</i>	€140,337	Tanzania
5	Genotyping of Mycobacterium leprae strains in leprosy patients and their close contacts for a better understanding of transmission in a high endemic leprosy district in Ceará State, Brazil.*	Mrs Ximena Illarramendi <i>Instituto Oswaldo Cruz (FIOCRUZ), Brazil</i>	€32,099	Brazil
1	Anti-M. leprae PGL-I IgM seroprevalence survey among children in Bihar, India <sup>§</sup>	Prof Annemieke Geluk <i>Leiden University Medical Center</i>	€10,000	The Netherlands

\*Projects accepted for partial funding (50%); <sup>§</sup>Seed funding, awarded as an output of a PEP workshop in 2019.

An overview of these and other current projects can be found on <https://leprosyresearch.org>

#### 4.2.1 Example project: Nerve function impairment and reactions

##### Efficacy and Tolerability of Adjunct Metformin in Combination with Standard Multidrug Treatment for Multibacillary Leprosy: A Randomized Double-blind, Controlled Proof-of-Concept Trial in Indonesia

Lead applicant	Dr Marlous Grijzen
Institute	Oxford University
Country	Indonesia
Start date	December 2020
Duration	48 months
Co-financing	Turing Foundation
Budget	€199,946

Presently, the standard treatment of leprosy is with a combination of three antibiotics, also referred to as multidrug therapy (MDT), often given for one year. Despite the fact that this treatment is effective in killing the bacteria, one of the main challenges is the occurrence of so-called leprosy reactions, which is a strong inflammatory response of the body's immune system to the leprosy infection. This can happen in about 30 to 50% of all patients, and cause nerve injuries leading to disabilities and deformities. Leprosy reactions are very difficult to treat as they are often chronic and recurrent. This means that many people who have a leprosy reaction need to use medicines that suppress the inflammation, called corticosteroids, for long periods of time. However, corticosteroids have many serious side-effects, such as diabetes, osteoporosis (reduced bone quality and density), psychological and eye problems, and make people susceptible to (severe) infections.

Therefore, this research proposal aims to investigate a new treatment strategy that can hopefully limit or prevent the development of leprosy reactions and its consequences. Based on previous studies in tuberculosis, which is caused by a similar bacterium, the researchers want to find out whether a medicine called metformin, if given in combination with standard MDT, can kill the leprosy bacteria faster, prevent or limit leprosy reactions, and thus reduce the need for corticosteroids.

Metformin is a cheap and safe drug that has been used for over decades in the treatment of people with diabetes, and is now receiving renewed interest as a promising drug that can have a positive effect on how the body's immune system reacts to infections.

Indonesia has the third highest number of people with leprosy in the world. A team of researchers from Indonesia and abroad proposes to conduct a clinical trial involving 110 people who have been newly diagnosed with multibacillary leprosy in Indonesia..

The study participants will be randomly divided (by chance) into two groups: one will receive metformin and the other will receive a placebo (an inert drug) for a period of half a year. Both groups will, at the same time, start with the standard MDT, given for a full year. Through this clinical trial, the research team hopes to find out whether the use of metformin is safe and well-tolerated by the volunteers on MDT treatment. They also hope to see that metformin could protect against the occurrence of leprosy reactions.

The overall aim of the project is to improve the treatment of patients with leprosy in the future, by preventing reactions and the development of disabilities, both in Indonesia and worldwide.

#### 4.2.2 Example project: Inclusion

##### Improving mental health and quality of life of persons affected by leprosy or Buruli ulcer in Southern Nigeria

Lead applicant	Dr Ngozi Ekeke
Institute	German Leprosy and Tuberculosis Relief Association, Nigeria
Country	Nigeria
Start date	July 2020
Duration	48 months
Co-financing	-
Budget	€199,933

Leprosy and Buruli ulcer (BU) co-exist in many States across Nigeria. Both are diseases of public health importance and are often associated with high levels of stigma and discrimination owing to their tendency to cause visible deformities. In 2018, Nigeria reported 2095 and 424 as number of persons suffering from leprosy and BU respectively.

Over time, stigma and discrimination negatively impact the well-being and mental health of persons with these diseases resulting especially in depression or anxiety. Mental health services in Nigeria suffer from multiple gaps: the lack of mental health services in general, the near absence of these services in rural areas as well as poor budgetary allocation by the government. This requires novel ways to make mental health services accessible to those in dire need, especially persons affected by leprosy and BU.

Previous research has shown that a community-oriented approach run by trained lay persons (without specialist mental health background) with appropriate supervision, can improve access to effective, acceptable and cost-effective mental health services.

This project has a dual objective. Firstly, to determine the burden/extent of mental illness among persons affected by leprosy or BU. Secondly, to ascertain whether a holistic (multi-layered) community-oriented approach involving patient self-help groups, lay community counsellors and non-specialist health workers improves the mental health and well-being of leprosy/BU patients in southern Nigeria.

During the 4-year project period, ten areas with highest number of leprosy/BU patients in southern Nigeria will be selected. In these selected areas, lay community counsellors will be trained. Subsequently the lay community counsellors will provide counselling to and promote social participation of patients diagnosed with depression or anxiety. Self-help groups will be established to provide an enabling platform for peer-support through regular interactions/meetings, reduce self-stigma and promote self-esteem among patients. Trained health workers will ensure effective treatment and/or adequate referral services for patients.

If successful, the model has the potential to be scaled up to more districts.

### 4.2.3 Example project: Transmission

#### Molecular Mechanisms of Immunomodulation Imparted by *Mycobacterium indicus pranii* (MIP) Against Multibacillary Leprosy.

Lead applicant	Dr Pushpendra Singh
Institute	ICMR-National Institute of Research in Tribal Health
Country	India
Start date	Tbd
Duration	48 months
Co-financing	Turing Foundation
Budget	€199,946

Leprosy has a wide range of clinical presentations. At one end of this spectrum, patients mount strong immune response with help of immune cells (Cell-Mediated Immunity) controlling bacterial numbers while at the other end of the clinical spectrum, immune cells are unable to mount any response to kill the invading bacilli leading to their enormous numbers in tissue. These patients where high number of bacilli are easily seen in microscopy are broadly referred to as multibacillary (MB) cases contribute to further transmission.

It is known that there is an improvement in treatment outcome in MB patients when the vaccine known as MIP (consisting of the autoclaved preparation of a saprophytic species *Mycobacterium indicus pranii*) is given

along with MDT, however the mechanisms of this improvement are not known.

This is a highly technical proposal that will help in understanding the immunological mechanisms of modulating immune cells in a way that augments their effectiveness when exposed to MIP and MDT.

To a large extent, the principle is generalizable to other vaccines, and hence, this approach can be useful for evaluating the efficacy of one vaccine vs another using a standardized work-flow and therefore the data from different studies involving different vaccines can be compared. This will help to establish intermediate endpoints for future vaccine trials.

### 4.3 Research projects completed

The independent Scientific Review Committee monitors progress of the funded projects bi-annually, during their Spring- and Autumn meeting. Using a standard check list the progress of the projects are assessed and financial reports reviewed. The SRC gives a recommendation about the progress and continuation of funding to the LRI Executives Group.

Three projects were completed in 2020:

**Patient Self-monitoring to detect nerve function impairment** (Grant: € 109,223; May 2017 - April 2020)

*Dr Marivic Balagon; Leonard Wood Memorial Center for Leprosy Research (Philippines)*

The goal of this project was to empower patients to conduct regular self-help monitoring using signs visible by the naked eye. This will encourage self-reporting resulting in prompt referral and treatment of complications preventing permanent nerve damage or onset of deformities.



It was a successful project that demonstrates the feasibility, field- applicability and patient acceptability of a lesion assessment tool; and that patients can reliably assess their own lesions to help identify incipient nerve damage. Furthermore, data suggest higher risk of abnormalities among nerves "near" inflamed lesions. These patients at risk require closer monitoring and prompt medical

attention for better treatment outcomes, preventing deformity.

The researchers are preparing a manuscript with their findings which we hope will soon be published.

**Intersectionality of inclusion** (Grant: €23,200; May 2018 - May 2020)

*Prof Irwanto; Atma Jaya Catholic University (Indonesia)*

The objective of this project was to gain insights in the dynamics around inclusion for different stigmatized health conditions (e.g. leprosy, HIV/AIDS, tuberculosis, mental illness, stigmatized Neglected Tropical Diseases) in different settings in Indonesia and to provide recommendations for generic and specific interventions and future implementation. It was a participatory and qualitative study using research methods such as interviews and focus group discussions.

This study was Erasmus Mundus Trans Global Health programme and has been highly successful. It has resulted in numerous publications, a PhD dissertation and the results were presented at a well-attended webinar including representatives from the Indonesia Ministry of Health.



**Family-based approaches self-management of disabilities – Ethiopia** Grant €130.380; April 2017 - January 2020

Mr Tesfaye Tadesse; Ethiopian National Association of People Affected by Leprosy (ENAPAL) (Ethiopia)

A key issue for persons affected is the life-long need to practice self-management routines. This is difficult to sustain without regular encouragement and support of others. Family-based support may be a sustainable and feasible strategy but has received little attention to date. This study aimed to develop a family-based approach to support prevention of disabilities in the Ethiopian context.

The family-based approach consists of (1) awareness raising, (2) disability management and (3) socio-economic empowerment. 275 persons affected (115 affected by leprosy and 160 affected by podocniosis or LF) and 255 of their family members were included in the pilot of the family-based approach. In this pilot project the researchers found that, compared to the situation before the intervention, the family-based approach had a positive impact on impairments, prevention of disabilities and self-management of disabilities.

Persons affected and family members were enthusiastic and positive about (participating

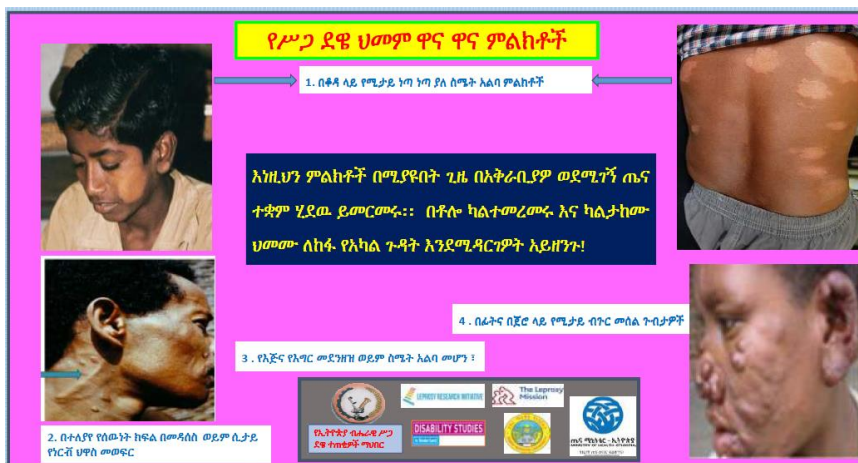
in) the approach. Family quality of life and stigma scores significantly improved after the intervention. The activity level scores decreased slightly but not significantly.

A number of articles were published which can be found on our website ([www.leprosyresearch.org](http://www.leprosyresearch.org)).

The outcome of this pilot project supported testing the approach in a controlled design. This proposal was submitted to the LRI and has been accepted for funding in the 2020 budget round (page 10, Mr Moges Wubie).

**Other completed project(s)**

The LRI values high scientific standards and capacity building and we realize that these do not always go hand in hand. At the same time we are accountable to our funding partners. Our grant award letters stipulate the circumstances in which we may terminate a grant, which we have done this year for the first time since our launch in 2013. It is not a decision we took lightly and we recognize the implications this has had for the research team involved and the participants of the study. The decision was taken after repeated concerns expressed by the Scientific Review Committee about the lack of progress in the project involved despite opportunities given to improve their performance.



Poster ENAPAL project

## 5 Capacity building

### 5.1 The LRI Spring Meeting and Workshops

The LRI Spring Meeting is a yearly event for LRI funded researchers – with the aim to present research updates to the LRI Scientific Review Committee (SRC) and the LRI Steering Committee (SC) and representatives from all funded research groups. The meeting also creates an opportunity to meet with and learn from fellow researchers and to share ideas between researchers, funders and other stakeholders. Traditionally, each project that started in the year before the meeting or earlier is invited to send a representative to present (interim) results to the members of the SRC, the SC and to each other.

The preparations for the 2020 Spring Meeting were well on their way when the COVID-19 pandemic hit. In agreement with the SC, the SRC and the Executive Group, the difficult decision was made to cancel the 2020 Spring Meeting, only 3 weeks before the event would take place.

Due to the COVID-19 pandemic and the travel restrictions, collaboration and sharing of information via online meetings and webinars boomed in 2020. However, our capacity strengthening workshops do not lend themselves easily for an online alternative. The goal of these workshops is to increase the quality of operational research proposals through capacity strengthening, aimed at teaching research methods, including proposal writing, with additional mentoring during the implementation phase. In the hope that 2021 would allow travel again – it was decided not to have an online workshop in 2020.



## 6 Other activities

### 6.1 The Global Partnership for Zero Leprosy

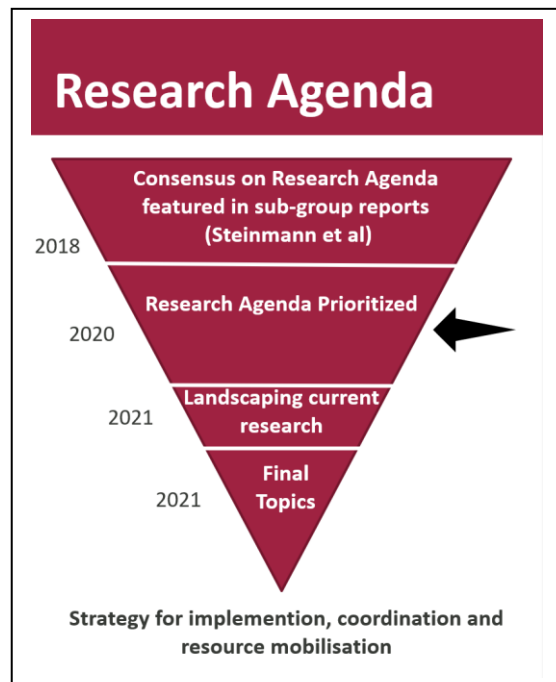
This year, the LRI supported the Global Partnership for Zero Leprosy (GPZL) in the prioritization of their research agenda.

In 2020, GPZL published the comprehensive research agenda for zero leprosy. It identified key priorities focused on (i) diagnostics, (ii) mapping, digital technology and innovation (iii) disability, (iv) epidemiological modelling and investment case (v) implementation research (vi) stigma, (vii) post exposure prophylaxis and transmission, and (viii) vaccines. It called for further priority-setting and coordination on protocol development as a means to mobilize resources to implement the research agenda.

The prioritization was set in the context of the WHO NTD Roadmap 2021 – 2030 and the GPZL Action Framework. A metric-based approach was used including the following criteria: impact, urgency, translational potential, feasibility, costs, time and novelty. To check for validity, the ranking results were compared with LRI’s previous stakeholder consultation (2018). Although LRI’s approach was different from the approach taken for the GPZL prioritization, the outcomes are nearly identical. The Top 10 research priorities will guide the subsequent activities to facilitate the development and design of research

accelerating towards zero leprosy, as well as resource mobilization initiatives.

Further collaboration on the research agenda with GPZL is foreseen for 2021.



## 6.2 Participant engagement

In 2018 the LRI conducted a stakeholders consultation to evaluate the research priorities. One of the findings of this project was that stakeholders advocated for enhancing the participation of persons affected by leprosy; in research, and in service delivery. In addition to developing models for enhancing participation and exploring the effect of such participation.

This resulted in a new LRI initiated research project that was conducted in 2020. The aim of this project was to identify how and when persons affected by leprosy could be effectively engaged during the research process from conception to implementation and dissemination. The project was performed as part of an MSc internship (Laura de Groot) at the VU University Amsterdam,

the Netherlands and consisted of a literature review, a survey among LRI funded researchers and key informant interviews. While there was agreement among the study participants about the importance of 'engagement', differences were found in the definition of meaningful engagements. Two arguments were most often listed as argument for engagement of persons affected, namely: improved reflection of their perspectives and improved knowledge translation. Knowledge about engagement strategies was the most frequently mentioned challenge. Further analyses of the findings will focus on enablers of engagements and strategies to improve engagement.

## 7 Current and Future perspectives

The call for proposals to be financed under the LRI 2021 budget was published in December 2019. For this call proposals addressing any of the five LRI research priorities were eligible for funding. In addition to the eligibility criteria, this call had a particular interest in studies which included specific strategies to improve the participation of persons affected in research and in studies which were in support of PEP implementation (across all priority areas).

Decisions about approvals for the budget 2021 were discussed in the Executives Group meeting of November 2020. These will be reported in the 2021 annual report.

In April 2021, the LRI Spring Meeting will be organized as an online event, of which a great advantage is that it will be open for a wider group of participants than the face-to-face meetings.

Other topics that will be addressed in 2021 include our capacity strengthening strategy

and the development of a guidance document on dissemination of research results.

The search for additional partners and new co-financiers of LRI approved research projects will continue in 2021. The need and requests for leprosy-related research still exceed the available budget of the LRI and its present co-financiers. With more LRI partners and leprosy research funding we can accelerate on our road to a world free from leprosy.

Collaboration with the Global Partnership for Zero Leprosy in the implementation of the research agenda will continue in 2021, maximizing our joint impact in promoting, facilitating and funding high-quality leprosy research.



LEPROSY RESEARCH INITIATIVE

Home Register Programme

# LRI Spring Meeting

April 8 (13:30-16:35 CET) and April 9 (13:30-17:00 CET) 2021

23 08 12 29  
Days Hours Mins Secs

Register Go to programme

## 8 Reviewer acknowledgements

We would like to thank all our external reviewers who dedicated their time to the peer review of the 2020 full proposals.

Linda Adams, USA

Valsa Augustine, India

Charlotte Avanzi, Switzerland

Indra Bahadur Napit, Nepal

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Zoica Bakirtzief da Silva pereira, Brazil

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John Belisle, USA

Marieke Boersma, the Netherlands

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Kathryn Dupnik, USA

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John Figarola, Brazil

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Silmara Pennini, Brazil

Cita Rosita Sigit Prakoeswa, Indonesia

Erwin Schurr, Canada

Maya Semrau, United Kingdom

Utpal Sengupta, India

Mahesh Shah, Nepal

Rahul Sharma, India

John Spencer, USA

Mariane Stefani, Brazil

Sharon Stevelink, United Kingdom

Cassandra White, USA

## 9 Who is who in the LRI

### Executives Group

The LRI Executives Group (EG) consists of the executive directors of the LRI partners.

Mr Jan van Berkel (until January 2021)	CEO, NLR (Chair)
Ms Linda Hummel (from January 2021)	CEO, NLR (Chair)
Ms Kim Evans (until July 2020)	CEO, effect:hope
Mr Burkard Kömm	CEO, GLRA
Mr Brent Morgan	CEO, TLMI
Mr Bill Simmons	CEO, ALM
Mr Alex Jaucot	CEO, Damien Foundation
Mr Iñigo Lasa (from November 2020)	General Director, Anesvad Foundation

### Steering Committee

The LRI is guided by a Steering Committee (SC). The SC membership comprises the research consultants or coordinators of the LRI partner organisations (ex-officio) and an independent Chair. The members in 2020 were:

Dr David Scollard	Retired Director of the USA National Hansen's Disease Programs (Chair)
Dr Wim H. van Brakel	Medical Director, NLR (Secretary)
Dr Peter Steinmann	Public Health Specialist and Epidemiologist, Swiss Tropical and Public Health Institute; Chair SRC R2Stop
Dr Christa Kasang	Research Coordinator, GLRA
Ms Jannine Ebenso	Head of Quality Assurance, TLMI
Dr Sunil Anand	Regional Director Asia, ALM
Dr Lucrecia Lacosta (from November 2020)	Associate professor at the University of Michael Hernandez de Elche (Spain), representative of Anesvad Foundation

The LRI SC is responsible to LRI Executives Group (EG).

### Scientific Review Committee

The quality, relevance and feasibility of submitted research proposals are assessed by the independent Scientific Review Committee (SRC), comprising experts in leprosy, clinical medicine, public health, rehabilitation and social sciences. This committee makes recommendations to the LRI EG concerning selection for funding. The SRC also monitors the progress of the ongoing projects. Members serve for a maximum of two terms (eight years). The SRC members in 2020 were:

Dr Richard Truman (Chair)	Retired Chief of the Laboratory Research Branch of the National Hansen's Disease Program, and Principal Investigator of the Leprosy Research Support program of the National Institutes of Allergy and Infectious Disease, USA
Dr Jos H.M. Dekker	Rehabilitation Physician, Heliomare Rehabilitation Centre at Red Cross Hospital, the Netherlands
Dr Gigi J. Ebenezer	Associate Professor, Neurology Department, Johns Hopkins School of Medicine, USA
Dr Bassey E. Ebenso	Research Fellow, Leeds University, Institute of Health Science, United Kingdom
Prof Dr Victor P.M.G. Rutten	Associate Professor at Department of Infectious Diseases and Immunology, University of Utrecht, the Netherlands and Extraordinary Professor at Department of Veterinary Tropical Diseases, University of Pretoria, South Africa
Prof Dr Maria Leide W.R. de Oliveira (until October 2020)	Professor of Dermatology, Federal University of Rio de Janeiro, Brazil
Prof Dr Françoise Portaels	Professor Emeritus, Institute of Tropical Medicine Antwerp Belgium
Prof Paul Fine (from April 2020)	Professor Emeritus of Communicable Disease Epidemiology, London School of Hygiene and Tropical Medicine, United Kingdom
Prof Dr Patricia D. Deps (from October 2020)	Full Professor at Department of Social Medicine, Postgraduate Programme in Infectious Diseases, Federal University of Espirito Santo, Brazil
Dr Zoica da Silva Pereira Bakirtzief (from October 2020)	Adjunct Associate Professor (External Professor), Psychology Department, Federal University of Santa Maria, Brazil

**Office team**

Dr Nienke Veldhuijzen  
Ms Nicole Dinnissen  
Ms Samira Musse  
Ms Linda van den Berg  
Mr Stephen Labib

Technical Officer  
Programme Officer  
Junior Officer  
Secretary  
Senior Communication Officer

## 10 Financial paragraph

### Summary Budget LRI 2021

Amounts x €1,000/ in Euro thousands

	<b>Budget 2021</b>
<b>Main Group</b>	
<b><u>Income:</u></b>	
- Income from contributors	1.179
- Income for co-financed projects	346
- Other income	0
- Income in return of goods and services	28
<b>Sum of income</b>	<b>1.553</b>
<b><u>Expenses:</u></b>	
-Research project costs	1.576
-Running costs (via NLR) and other operating expenses	270
<b>Sum of expenses</b>	<b>1.846</b>
<b>Result</b>	<b>(293)</b>

*Please refer to the annual accounts of LRI for the detailed budget of 2021.*

### Financial results 2020

In 2020 LRI received a total contribution from partners of €1,003,450 and in addition to this an amount of €94,087 was received from Turing Foundation and other partners towards running costs and research projects. The total expenses arrived at €760,338. The positive result of 2020 amounting to €347,187 is added to the earmarked reserves of LRI. This increased the total earmarked reserves from €632,312 to €979,499. The earmarked reserves are formed in accordance with LRI policy, please refer to the notes accompanying the annual account for 2020 for LRI policy.

The freely available funds consist of cash held in the bank account and amount to €1,581,805 as per 31 December 2020.

### Outlook 2021

LRI will receive a contribution of €1,179,000 from partners, an amount of €346,000 for co-financed projects and €28,000 in return of goods and services. The expected expenditures will be €1,846,000. Looking forward, we expect a certain growth in project activities. However with the COVID-19 pandemic still ongoing, and the (partial) lockdowns in many countries, LRI expects again that the pandemic will also leave its mark in 2021 and will not return to pre-COVID-19 level before 2022.

Please refer to the year plan of LRI published on the website for the detailed budget and a detailed description of the activities in 2021.



# Annual Accounts 2020

**Leprosy Research Initiative (LRI)**

Amsterdam, The Netherlands

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## I. Balance sheet as at 31 December 2020

Amounts in Euros

	Notes	31-Dec-20	31-Dec-19
<b>ASSETS</b>			
<i>Fixed assets</i>			
Tangible fixed assets	1.	€ 0	€ 0
		€ 0	€ 0
<i>Current assets</i>			
Accounts receivable	2.	€ 16.796	€ 4.233
Contributions due		€ 0	€ 85.696
Paid in advance		€ 0	€ 44.789
Cash and cash equivalents		€ 1.581.805	€ 1.067.588
		€ 1.598.602	€ 1.202.305
<b>Total assets</b>		€ 1.598.602	€ 1.202.305
<b>LIABILITIES</b>			
<i>Reserves</i>			
Continuity reserves	3.	€ 0	€ 0
Earmarked reserves		€ 979.499	€ 632.312
		€ 979.499	€ 632.312
<i>Short-term liabilities</i>			
Accounts payable	4.	€ 394.781	€ 424.799
Deposits		€ 0	€ 12.298
Balances and accounts to NLR		€ 224.321	€ 132.896
		€ 1.598.602	€ 1.202.305
<b>Total liabilities</b>		€ 1.598.602	€ 1.202.305

## Annual Accounts LRI 2020

### II. Statement of Income and Expenses for the year 2020

Amounts in Euros

	Notes	Realisation 2020	Budget 2020	Realisation 2019
<b>INCOME:</b>	5.			
Income from allied and joint non-profit organisations	€	1.003.450	€ 1.090.000	€ 1.104.141
Other income	€	94.087	€ 395.000	€ 300.846
Income in return of goods and services	€	9.986	€ 0	€ 0
<b>Total income</b>	€	<b>1.107.524</b>	€ <b>1.485.000</b>	€ <b>1.404.986</b>
<b>EXPENSES:</b>	6.			
Research project costs	€	527.364	€ 1.332.453	€ 1.387.868
Staff costs, housing and office costs	€	210.475	€ 173.000	€ 192.461
Other operating expenses	€	22.499	€ 70.000	€ 29.703
<b>Total expenses</b>	€	<b>760.338</b>	€ <b>1.575.453</b>	€ <b>1.610.031</b>
<b>Result of income and expenses</b>	€	<b>347.187</b>	€ <b>-90.453</b>	€ <b>-205.045</b>

### **III. Notes accompanying the annual account for 2020**

#### **a. General and accounting policies**

This is the annual account of 2020 of LRI (Leprosy Research Initiative). LRI has been registered since June 1st 2015 as a foundation under Dutch law. From the 1st of January of 2015 LRI has taken over all activities from Netherlands Leprosy Relief (NLR). This is the annual account of LRI presented for the year 2020, which started on the 1st of January and ended December 31st. LRI is registered at Chamber of Commerce no. 3431874.

#### **General note on the accounting policies**

The annual account has been prepared in accordance with Guideline C for small non-profit organisations (Dutch: Richtlijn C1 Kleine organisaties zonder winststreven) as published by the Dutch Accounting Standards Board (Raad voor de Jaarverslaggeving) and revised in 2016.

#### **Activities**

LRI (Leprosy Research Initiative) is a combined venture of NLR, American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief Association (GLRA), effect:hope (The Leprosy Mission Canada) and The Leprosy Mission International (TLMI). Guided by an allied policy with clearly defined research priorities, the partners have established a joint fund to support leprosy research. The joint fund is reserved for research that is exclusively or strongly related to leprosy. A comprehensive explanation of our mission and goals and a detailed account of the content of our work can be found in our annual report.

#### **LRI work proceedings and work activities**

LRI fully delegated all its work proceedings and activities to NLR. NLR runs Leprosy Research Initiative's secretariat and all work proceedings and activities are also performed by NLR. The Supervisory Board of NLR supervises the proceedings and activities as reported by the NLR Director.

#### **Registered address**

The registered and actual address of LRI is Wibautstraat 137k, 1097 DN in Amsterdam, The Netherlands.

#### **Accounting period**

The annual accounts have been drawn up for an accounting period of one year. The financial year is equal to the calendar year. The annual accounts have been prepared on a historical cost basis of accounting.

#### **Accounting policies for the valuation of assets and liabilities and the determination of the result**

All amounts in the annual accounts are in Euros or a multiple of 1,000 Euro, or rounded to the nearest amount in Euros. The amounts are compared to the part for research activities and objectives from the formal LRI budget for 2020 (approved by the Supervisory Board of NLR in December 2019).

The annual accounts have been prepared in accordance with the principle of continuity.

### **Income from funding and the allocation of funds**

Each LRI partner has committed an annual contribution to LRI research fund and contributes an equal share to LRI running costs. The income from partners, associate partners, contributors and co-financiers are recognised in the year to which the item of income relates and are allocated to the year in question on an actual cost basis. The income is shown gross, before any deduction of associated costs, unless otherwise stated. Necessary costs to realise certain benefits, are presented in the statement of income and expenses as expense.

### **Grand commitments**

The grant commitments are recognised as conditional commitments. LRI receives from the partners, 2 progress reports annually, including scientific progress regarding the Research and financial statements: a semi-annual report and an annual report. The semi-annual report must be submitted each year on September 1st. The deadline for submission of the annual report is March 1st. The amounts that are expected to be settled within one year and are accounted insofar as expenditures are appropriate within the condition and as short-term liabilities. LRI does not hold any long-term liabilities.

### **Accounts receivable**

Receivables are initially valued at the fair value of the consideration to be received, including transaction costs if material.

### **Cash and cash equivalents**

Cash and cash equivalents include cash and bank balances represent the balance of the bank account held for the head office of LRI, in the Netherlands and are immediately accessible. LRI does not have any borrowings or loans. LRI does not invest nor does it make use of any financial instruments.

### **General note on the balance sheet and statement of income and expenses**

In general, assets and liabilities are stated at the amounts at which they were acquired or incurred, or current value. If not specifically stated otherwise, they are recognised at the amounts at which they were acquired or incurred. The balance sheet and statement of income and expenses include references to the notes. Notes to the line items of the balance sheet and the statement of income and expenses have been numbered in the financial statements.

### **Foreign currency**

The annual accounts are presented in Euro. Transactions in foreign currency are converted to Euro at the exchange rate of the transaction date.

### **Reserves**

LRI ensures that contributions are used for the intended cause. If more money is received for a specific research project than needed in that particular year for that project, LRI will allocate this money to the same project in the following year. If LRI no longer supports the project the following year, LRI will use the funds for a similar project. In the event there are no such projects, the money will be deposited in the general joint fund or it will be refunded to the contributor. The reserves are the result of income and expenses and is held in accordance with budgets for (scientific) research and running costs of LRI for future years to ensure sustainability of LRI so that its projects proceedings and activities are not affected and to grant new research project proposals. The surplus amounts are retained in as safe as possible bank accounts with trustworthy banks. The result of 2020 is added to the earmarked reserves, set aside for future funding of LRI projects. LRI holds no investments.

### **Management of LRI and remuneration of Supervisory Board and Executive Group**

LRI is managed by the director of NLR, implementing the decisions of LRI Executive Group and supervised by the Supervisory Board of NLR. No remuneration was paid to the Supervisory Board members and director of NLR, and no loans, advances or guarantees were given. In 2020 no expenses were reimbursed.

### **Events after the reporting period**

In these accounts no significant events after the reporting period occurred which should be included.

### **Publication**

This report is available on [www.leprosyresearch.org](http://www.leprosyresearch.org). The 2020 annual report and the annual accounts are available in a digital format primarily for environmental reasons. A (free of charge) printed copy can be obtained on request.

### III b. Notes to the Balance sheet 2020

#### 1. Tangible fixed assets

Tangible fixed assets are used for the main activities and entirely held for operational management. LRI holds no tangible fixed assets and therefore this is not valued in 2020. Also in 2019 no tangible fixed assets were acquired.

#### 2. Current Assets

This item includes all receivables which are due within one year, amounts paid in advance and cash and cash equivalents.

	31 December 2020	31 December 2019
	in €	in €
Contributions and amounts due	16.796	89.929
Paid in advance	-	44.789
Cash and cash equivalents	<u>1.581.805</u>	<u>1.067.588</u>
	<u><b>1.598.602</b></u>	<u><b>1.202.305</b></u>

The income from contributions are accounted for once the commitment has been confirmed. The item contributions and amounts due relate to the contribution of NLR towards the ALM LepVax research project, this amount is expected but not yet received income.

Cash and cash equivalents are cash and bank balances in Euros in the Netherlands held by LRI office in Amsterdam. LRI holds its main current account at ING Bank (NL). The balance of cash and cash equivalents are available immediately. The cash and cash equivalents balance for the year ended 31 December 2020 is € 1,581,805.

#### 3. Reserves

The reserves are the result of income and expenses and are held in accordance with budgets for (scientific) research and running costs of LRI for future years to ensure sustainability of LRI so that its projects proceedings and ongoing activities are not affected and also to grant to new research project proposals.

	31 December 2020	31 December 2019
	in €	in €
Earmarked reserves	<u>979.499</u>	<u>632.312</u>
	<u><b>979.499</b></u>	<u><b>632.312</b></u>

#### General notes on the reserves

- For the budget of 2020, a deficit of nearly € 90,000 was accounted. The COVID-19 pandemic not only has a major impact on our lives, but certainly also on our organisation and the research project and activities in the field. The majority of the projects were temporarily shut down and delayed in execution and progress. Also the impact differs per project. LRI decided to respond to the needs of the project holders by extending the project duration and offer the possibility of a no-cost extension to continue activities related to the grant awarded originally. The positive result of 2020 arrived at € 347,187 and is added to the earmarked reserves of LRI.

- LRI ensures that contributions are used for the intended cause. If more money was received for a specific research project than needed in that particular year for that project, LRI will allocate this money to the same project in the following year. From the total amounts received in 2020, a few partners contributed to specific research projects which remained unspent in 2020. The majority of these funds has been allocated to activities in 2021. These consist of financing the current projects, award new research projects and a proportional part for financing LRI organisation.

- LRI holds no continuity reserve.

LRI's reserves are as follows:

Balance as per 1 January 2020  
 - Movements  
 - Withdrawals and additions  
 Balance as per 31 December 2020

Continuity reserves	Earmarked reserves	Total
in €	in €	in €
0	632.312	632.312
0	0	0
0	347.187	347.187
<b>0</b>	<b>979.499</b>	<b>979.499</b>

#### 4. Short-term liabilities

All current liabilities fall due in less than one year. The fair value of the current liabilities approximates the book value due to its short-term character.

##### Accounts payable

	31 December 2020	31 December 2019
	in €	in €
Accounts payable/creditors	<u>394.781</u>	<u>424.799</u>
	<b><u>394.781</u></b>	<b><u>424.799</u></b>

Accounts payable are mainly amounts payable to the amount of € 58,000 for (scientific) research in 2020, not yet formally invoiced by the researchers and institutes concerned. This item also concerns fees (€ 6,000) for the independent external auditor Dubois who performs the audit. These are paid in the first half year of 2020 by LRI. The amounts received in advance (€ 330,000) are also calculated under this item, which are unspent funds from Turing Foundation and other contributors towards research projects.

##### Deposit

	31 December 2020	31 December 2019
	in €	in €
Deposit/Funds to be returned	<u>-</u>	<u>12.298</u>
	<b><u>-</u></b>	<b><u>12.298</u></b>

In 2020 no amounts were deposited.

##### Balances and accounts to NLR

	31 December 2020	31 December 2019
	in €	in €
	<u>224.321</u>	<u>132.896</u>
	<b><u>224.321</u></b>	<b><u>132.896</u></b>

The amount of € 224,321 reflects to the debt LRI has towards NLR. This amount has been settled in 2021. Compared to the balance in 2019, the realisation in 2020 is higher, because NLR fully contributed their annual contribution, which led to a lower debt in funds to receive from NLR. The amount of € 224,321 consists of salaries, charged support costs and other costs paid in advance by NLR.



**Commitments not included in the balance sheet**

LRI has made commitments for 2021 and beyond for running research projects for a total value of € 1,758,693.

**Events after balance sheet date**

COVID-19 response measures have impacted the whole environment. LRI is also confronted with the consequences. The response measures might affect the realisation of the budget for the year 2021. The impact is difficult to quantify at this stage. The reserve and liquidity position are considered to be sufficient to compensate for the possible negative consequences. As a result, it does not affect the annual accounts 2020 and the continuity of LRI.

### III c. Notes to the Statement of Income and Expenses 2020

Amounts in Euros

#### 5. Income

Each LRI partner has committed an annual contribution to the joint LRI research fund and contributes an equal share to LRI running costs. In 2020 the partners were: American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief Association (GLRA/DAHAW), effect:hope (The Leprosy Mission Canada), The Leprosy Mission International (TLM), Action Damien and NLR. The breakdown of the total income is as follows:

		Realisation 2020	Budget 2020	Realisation 2019
		in €	in €	in €
Income from allied and joint non-profit organisations	ALM	165.000	130.000	273.798
	effect:hope	33.450	135.000	137.743
	GLRA/DAHAW	185.000	185.000	183.800
	TLM International	135.000	135.000	133.800
	The Mission to End Leprosy	0	20.000	0
	NLR	350.000	350.000	350.000
	Action Damien	135.000	135.000	25.000
Other income	Turing Foundation	90.259	310.000	162.620
	Others	3.828	85.000	138.226
Income in return of goods and services	Others	9.986	0	0
		<u>1.107.524</u>	<u>1.485.000</u>	<u>1.404.986</u>

The total amount available for allocation in line with the objectives for 2020 arrived at: € 1,107,524.

The realisation of the total income in 2020 was 25% lower than budgeted. Action Damien and Anesvad Foundation joined LRI in 2020. In 2020 effect:hope ended the partnership and has withdrawn their support to LRI due to lack of funds partly as a consequence of the financial impact of the COVID-19 pandemic. Anesvad Foundation will contribute to the joint fund and running costs from 2021. From the Turing Foundation we received a contribution for the running costs of LRI to the amount of € 10,474 and € 79,785 towards specific research projects. The Turing Foundation contributes five percent of their actual co-funded allocated budget on project funding towards running costs as realised at the end of the year 2020. The amount under other income from others consists of surplus funds that were received after completing projects. The amount under income in return of goods and services consists of the fees for outsourced work.

#### 6. Expenses

The expenses mainly consist of funding of (scientific) research project costs. A total of 29 research projects have been funded in 2020. Six of these projects were completed in 2020. The annual Spring meeting and different workshops were cancelled due to the COVID-19 pandemic. Please refer to the overview of research costs on page 11 for the specification of the project expenses. LRI has spent a total of € 760,337 (2019: € 1,610,032) on research funding and running costs.

	Realisation 2020	Budget 2020	Realisation 2019
	in €	in €	in €
<i>Research</i>			
- Research projects funding	527.363	1.332.453	1.387.868
	<u>527.363</u>	<u>1.332.453</u>	<u>1.387.868</u>

The actual research project costs were 74% lower than budgeted due to the impact of the unusual circumstances of the COVID-19 pandemic. Our priority remains to ensure that LRI funded research projects are fully supported towards completion. To tackle this under-spending most of the projects applied for a no-cost extension to their grants during this pandemic. The no-cost extension allows the use of existing grants flexibly but LRI will not provide supplementary funding towards on-going projects. The research project overview on page 11 specifies the granted funds per (scientific) research project.

The executive institutions of 9 out of 29 research projects determined that additional time is needed to meet the objectives of the awarded grant and applied for a no-cost extension, extending the project period beyond the original project end date without additional funding. LRI has approved the requests of the grantees in accordance with LRI policy, allowing the completion of the projects in 2020. Therefore payment for these projects in 2020 is postponed and will take place in 2021 upon continuation and completion of the project.

	<b>Realisation 2020</b>	<b>Budget 2020</b>	<b>Realisation 2019</b>
	in €	in €	in €
<i>Running costs</i>			
- Staff expenses	175.475	173.000	168.416
- Housing expenses	19.000	19.000	16.500
- Office expenses	16.000	16.000	7.545
- Other operating expenses	22.499	35.000	29.703
	<u><b>232.974</b></u>	<u><b>243.000</b></u>	<u><b>222.164</b></u>

LRI has no staff members, all staff is employed by NLR. NLR runs LRI's secretariat, therefore the running costs mainly involves wages, salaries, pension costs (insured with Pensioenfonds Zorg en Welzijn), social security charges to the amount of € 175,475 and other charged support costs for LRI secretariat officers to the amount of € 35,000. These costs are reimbursed to NLR. In 2020 on average 2.4 FTEs (2019: 2.1 FTEs) were employed via NLR in the secretariat of LRI in Amsterdam. LRI has no staff employed abroad during 2020. For LRI officers the NLR standard terms, benefits and conditions of employment apply.

The staff costs for LRI officers arrived at € 175,475 and can be specified as follows:

	<b>Realisation 2020</b>	<b>Budget 2020</b>	<b>Realisation 2019</b>
	in €	in €	in €
Wages and salaries	136.767	130.000	128.634
Social security costs	21.948	22.000	21.162
Pension contributions	14.894	15.000	12.991
Other personnel costs	1.867	6.000	5.629
	<u><b>175.475</b></u>	<u><b>173.000</b></u>	<u><b>168.416</b></u>

In addition to these staff costs for LRI officers, the running costs also consist of the housing and general office expenses that cannot be directly allocated to the research projects this is presented under the item housing and general office expenses and arrived at € 35,000 in 2020 (2019: € 24,045). The realisation of housing and office expenses of 2020 was in accordance with the budget and expected to be higher due to an increase in housing and general office costs. The total staff costs of LRI amount to € 175,475. Towards the running costs Turing Foundation contributed € 10,474 and GPZL contributed € 9,986 towards staff costs for 2020. These amounts are presented according the classification as income (note 5).

Other information

**<Independent Auditor's Report>**

## INDEPENDENT AUDITOR'S REPORT

To: the Management Board and the Supervisory Board of Stichting Leprosy Research Initiative in Amsterdam, The Netherlands.

### A. Report on the audit of the financial statements 2020 included in the annual report

#### Our opinion

We have audited the financial statements 2020 of Stichting Leprosy Research Initiative based in Amsterdam, The Netherlands.

In our opinion the accompanying financial statements give a true and fair view of the financial position of Stichting Leprosy Research Initiative as at 31 December 2020 and of its result for 2020 in accordance with the Guidelines for annual reporting C1 "Small not-for-profit organisations" of the Dutch Accounting Standards Board.

The financial statements comprise:

1. the balance sheet as at 31 December 2020;
2. the statement of income and expenses for 2020; and
3. the notes comprising a summary of the accounting policies and other explanatory information.

#### Basis for our opinion

We conducted our audit in accordance with Dutch law, including the Dutch Standards on Auditing. Our responsibilities under those standards are further described in the 'Our responsibilities for the audit of the financial statements' section of our report.

We are independent of Stichting Leprosy Research Initiative in accordance with the Verordening inzake de onafhankelijkheid van accountants bij assurance-opdrachten (ViO, Code of Ethics for Professional Accountants, a regulation with respect to independence) and other relevant independence regulations in the Netherlands. Furthermore we have complied with the Verordening gedrags- en beroepsregels accountants (VGBA, Dutch Code of Ethics).

We believe the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

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## **B. Report on the other information included in the annual report**

In addition to the financial statements and our auditor's report thereon, the annual report contains:

- the Management Board's report;
- Annex 1: Overview of research projects with budget comparison 2020;
- Annex 2: Budget Stichting Leprosy Research Initiative (LRI) 2021;
- Annex 3: Multi Annual Budget Stichting Leprosy Research Initiative (LRI) 2021-2023;
- Annex 4: Management Board and Executives Group

Based on the following procedures performed, we conclude that the other information is consistent with the financial statements and does not contain material misstatements.

We have read the other information. Based on our knowledge and understanding obtained through our audit of the financial statements or otherwise, we have considered whether the other information contains material misstatements.

By performing these procedures, we comply with the requirements of the Dutch Standard 720. The scope of the procedures performed is substantially less than the scope of those performed in our audit of the financial statements. Management is responsible for the preparation of the other information, including the Management Board's report, in accordance with the Guidelines for annual reporting C1 "Small not-for-profit organisations" of the Dutch Accounting Standards Board.

## **C. Description of responsibilities regarding the financial statements**

### **Responsibilities of the Management Board and the Supervisory Board for the financial statements**

The Management Board is responsible for the preparation and fair presentation of the financial statements, in accordance with the Guidelines for annual reporting C1 "Small not-for-profit organisations" of the Dutch Accounting Standards Board. Furthermore, the Management Board is responsible for such internal control as the Management Board determines is necessary to enable the preparation of the financial statements that are free from material misstatement, whether due to fraud or error.

As part of the preparation of the financial statements, the Management Board is responsible for assessing the foundation's ability to continue as a going concern. Based on the financial reporting framework mentioned, the Management Board should prepare the financial statements using the going concern basis of accounting unless management either intends to liquidate the foundation or to cease operations, or has no realistic alternative but to do so.

The Management Board should disclose events and circumstances that may cast significant doubt on the foundation's ability to continue as a going concern in the financial statements.

The Supervisory Board is responsible for monitoring the financial reporting process of the organisation.

### **Our responsibilities for the audit of the financial statements**

Our objective is to plan and perform the audit assignment in a manner that allows us to obtain sufficient and appropriate audit evidence for our opinion.

Our audit has been performed with a high, but not absolute, level of assurance, which means we may not detect all material errors and fraud during our audit.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements. The materiality affects the nature, timing and extent of our audit procedures and the evaluation of the effect of identified misstatements on our opinion.

We have exercised professional judgement and have maintained professional scepticism throughout the audit, in accordance with Dutch Standards on Auditing, ethical requirements and independence requirements.

Our audit included e.g.:

- identifying and assessing the risks of material misstatement of the financial statements, whether due to fraud or error, designing and performing audit procedures responsive to those risks, and obtaining audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- obtaining an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the foundation's internal control;
- evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Management Board;
- concluding on the appropriateness of management's use of the going concern basis of accounting, and based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause a foundation to cease to continue as a going concern;
- evaluating the overall presentation, structure and content of the financial statements, including the disclosures; and
- evaluating whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant findings in internal control that we identify during our audit.

Amsterdam, 30 June 2021

Dubois & Co. Registeraccountants

A.P. Buteijn RA

**annex 1 Overview of research projects with budget comparison 2020**

Amounts in Euros

<b>Project number</b>	<b>Current research projects</b>	<b>Budget 2020</b>	<b>Realisation 2020*)</b>
703.15.41	TLM Nepal/Helminth influences in leprosy (1 sept 2015 - 31 Aug 2019)/Hage	20.000	0
704.16.59	MSU/Biomarkers for early detection of leprosy, India/US /Singh (1 Jan 2017/ 31 December 2020)	11.000	0
704.16.71	ENLIST MTX - two randomised controlled trials in ENL, Walker (1 Nov 2016- 31 Oct 2022)	233.542	0
705.17.07	LWM/Inflamed Skin Lesions Along an Area of a Peripheral Nerve, Phillipines (1 May 2017 - 30 April 2020)	10.923	10.923
705.17.30	ENAPAL/Family-based approaches self-management of disab. due to leprosy, podoconiosis and LF/Ethiopia	13.038	16.101
705.17.41	SIH-R & LC/Mobile Technology (M-Health) India (1 March 2017 - 28 Feb 2020)	3.590	0
706.18.39	PUCPR/Functional analysis of candidate variants in the early-onset leprosy phenotype using novel cellular model	19.644	0
706.18.46	FUSM/ILEP Promoting inclusion where it matters most: Building resilience in individuals and families, Brazil/India	3.018	0
706.18.20	VU Amsterdam/Intersectionality of inclusion	2.600	2.584
706.18.29	SIHR&LC/Design a customized offloading devices to promote healing of plantar ulcers – India	3.550	0
706.18.45	Athena Institute/A qualitative and participatory research to improve the management of ENL – Indonesia/India	6.340	5.379
706.18.52	FAIRMED/Integrated strategy for early detection of leprosy and other NTDs, Cameroon	39.624	(33.210)
706.18.57	EUSM/Describing metabolic profiles in leprosy and its morbidities using plasma metabolomics, Brazil	13.955	0
707.19.02	Erasmus MC/Monitoring effect of prophylactic interventions, Bangladesh	75.000	93.750
707.19.20	IRDBP/Implementation of Dapsone Hypersensitivity Syndrome, Indonesia/Nepal	66.226	21.958
707.19.45	DF/Assessing the effectiveness of IECS, Bangladesh	39.500	39.500
707.19.60	NLTB/Collaboration traditional healers, Sierra Leone	54.703	15.626
707.19.62	NCGM/Integrated approach skin camp, eSkin Health app, Côte d'Ivoire	37.953	9.488
707.19.21	BLP/Clofazimine for MB cases at high risk of ENL, Bangladesh/India	49.264	71.627
707.19.64	ALM/LepVax	100.000	0
709.00.20	SRC/LRI spring & autumn meetings	85.000	13.604
706.18.99	Workshop on operational research	34.000	0
708.20.04	Efficacy and Tolerability of Adjunct Metformin in Multidrug Treatment	59.620	29.727
708.20.09	Molecular Mechanisms of Immunomodulation Imparted by Mycobacterium indicus pranii (MIP)	60.690	0
708.20.12	Informing (generic) approaches to reduce stigma: Capturing culture-specific stigma dynamics by understanding 'What matters most'	55.119	111.055
708.20.14	Leprosy Antimicrobial Resistance Surveillance in Post Exposure Prophylaxis Setting in Tanzania (LARS)	66.218	0
708.20.15	Improving mental health and Quality of Life of Persons affected by Leprosy or Buruli ulcer in Southern Nigeria	52.185	58.549
708.20.17	Assessing the long-term outcomes and sustainability of family-based approaches	44.283	44.512
707.19.56	Internship Participant engagement (2020)	0	3.701
708.20.18	Genotyping of Mycobacterium leprae strains in leprosy patients and their close contacts for a better understanding of transmission	51.868	0
	Write workshop (2020)	20.000	0
	Other project costs (to NLR)	0	12.490
	<b>Total research costs for current projects</b>	<b>1.332.453</b>	<b>527.363</b>
	<b>TOTAL PROJECTS</b>	<b>1.332.453</b>	<b>527.363</b>

The total amount for 2020 towards projects was budgetted to € 1,332,453. This amount consist of € 294,443 co-funding finances from the Turing Foundation.

\*) This overview shows the actual project costs. The Turing Foundation contributed € 79,785 towards research projects.



**Budget Stichting Leprosy Research Initiative (LRI) 2021**

Amounts x €1,000/ in Euro thousands

Main Group	Specification	Budget 2021	Realisation 2020	Budget 2020
<b><u>Income:</u></b>				
- Income from contributors *)	ALM	168	165	130
	Action Damien	135	135	135
	effect:hope	0	33	135
	GLRA/DAHW	188	185	185
	TLM International	138	135	135
	The Mission to End Leprosy	0	0	20
	Anesvad Foundation	200	0	0
	NLR	350	350	350
- Other income	Turing Foundation	301	90	310
	Income for co-financed projects	45	0	85
	Income from others	0	4	0
	Income in return of goods and services	28	10	0
<b>Sum of income</b>		<b>1.553</b>	<b>1.108</b>	<b>1.485</b>
<b><u>Expenses:</u></b>				
<b>Expenses on the Objectives:</b>				
- Research project costs		1.576	527	1.332
	<b>TOTAL RESEARCH PROJECTS BUDGET</b>	<b>1.576</b>	<b>527</b>	<b>1.332</b>
-Running costs (via NLR) and other operating expenses		270	233	243
		<b>270</b>	<b>233</b>	<b>243</b>
<b>Sum of expenses</b>		<b>1.846</b>	<b>760</b>	<b>1.575</b>
<b>Result</b>		<b>(293)</b>	<b>347</b>	<b>(90)</b>
Accumulated joint fund balance 2020			<b>(205)</b>	
Accumulated joint fund balance 2021			<b>347</b>	

annex 3

**Multi Annual Budget Stichting Leprosy Research Initiative (LRI) 2021-2023**

Amounts x €1,000/ in Euro thousands

This overview shows the budget and projection for the upcoming three years:

	<b>Budget 2021</b>	<b>Projection 2022</b>	<b>Projection 2023</b>
<b>Income:</b>			
Income from contributors	1.179	1.120	1.120
Income for co-financed projects	346	270	224
Income in return of goods and services	28	0	0
<b>Sum of income</b>	<b>1.553</b>	<b>1.390</b>	<b>1.344</b>
<b>Expenses:</b>			
<b>Expenses on the Objectives:</b>			
- Approved Leprosy research projects (ongoing)	1.065	1.204	810
- Funding of new research projects	511	0	0
	<b>1.576</b>	<b>1.204</b>	<b>810</b>
<b>Running costs</b>	<b>270</b>	<b>245</b>	<b>248</b>
	<b>270</b>	<b>245</b>	<b>248</b>
<b>Sum of expenses</b>	<b>1.846</b>	<b>1.449</b>	<b>1.058</b>
<b>Result</b>	<b>(293)</b>	<b>(59)</b>	<b>287</b>
	=====	=====	=====

## annex 4

### Leprosy Research Initiative (LRI)

#### Management Board

	From	Until
NLR	01/06/2015	

#### Executives Group

The LRI Executives Group (EG) consists of the executive directors of the LRI partners.

Mr B. Simmons  
Chief Executive Officer; American Leprosy Missions

Mr B. Kömm  
Chief Executive Officer; German Leprosy Relief Association

Ms K. Evans  
Chief Executive Officer; effect:hope (until July 2020)

Mr B. Morgan  
Chief Executive Officer; The Leprosy Mission International

Mr A. Jaucot  
Chief Executive Officer; Damien Foundation

Mr J. van Berkel Chief Executive Officer; NLR (Chair)	01/06/2015	31/12/2020
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Ms L. Hummel Chief Executive Officer; NLR (Chair)	01/01/2021	
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