



# LEPROSY RESEARCH INITIATIVE



**Annual Report 2019**

## Contents

<b>1. Introduction</b>	3
<b>2. Vision and Policy</b>	4
<b>3. Research</b>	6
3.1 Proposals received and approved	6
3.2 New research projects funded	8
3.2.1 Example project: Early detection	10
3.2.2 Example project: Nerve function impairment and reactions	11
3.2.3 Example project: Transmission	12
<b>4. Capacity building</b>	13
4.1 The LRI Spring Meeting	13
4.2 Operational Research Workshop	14
4.3 PEP workshop	15
<b>5. Other activities</b>	16
5.1 International Leprosy Conference	16
<b>6. Current and Future perspectives</b>	17
<b>7. Who is who in the LRI</b>	18
<b>8. Financial paragraph</b>	20
<b>9. Annual Accounts</b>	21

**Postal address**  
P.O. Box 95005  
1090 HA Amsterdam  
The Netherlands

**Visiting address**  
Wibautstraat 137k  
1097 DN Amsterdam  
The Netherlands

**E-mail** [info@leprosyresearch.org](mailto:info@leprosyresearch.org)  
**Internet** [www.leprosyresearch.org](http://www.leprosyresearch.org)

## 1. Introduction

This is the fifth Annual Report of the Leprosy Research Initiative (LRI). The LRI, founded in 2013, is a unique model of cooperation and coordination in funding leprosy research. Since its launch, five international NGOs committed to work towards zero leprosy combine their funding for research in a joint fund under one policy.

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 2019. The financial proceedings have been audited by an independent auditor.

In 2019 the LRI allocated about €1.8 million to 33 research projects. Included in this amount is the very substantial contribution of close to €152,000 by the Turing Foundation as co-financier of the LRI.

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

- American Leprosy Missions (ALM)
- German Leprosy Relief Association (GLRA)
- effect:hope
- The Leprosy Mission International (TLMI)
- NLR

The Mission-to-End-Leprosy continued its support to the running costs of the LRI in 2019. New this year was the contribution by Damien Foundation.

The LRI partners have confirmed their participation in the LRI for a minimum of three years and have agreed to decide annually about extension of this three year

commitment by another year. In 2019, the partners have therefore extended their commitments until the end of 2021.

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, without whom it would not have been possible to achieve these results.

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 2019 via personal involvement, financial support or co-operation.

Jan van Berkel  
Director

Bram van Ojik  
Chair NLR  
Supervisory Board

## 2 Vision and Policy

### **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**

1. To establish and maintain a joint research fund to support leprosy research that fits with the LRI priorities.
2. 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**

1. To facilitate the development of research funding proposals in collaboration with concerned research groups.
2. To establish and maintain a joint research fund for leprosy research.
3. To facilitate adequate resourcing of leprosy research projects.
4. To provide an efficient, transparent and scientifically rigorous selection process of research proposals that fit the priorities set in the joint research policy.
5. To provide a scientifically high-quality monitoring mechanism of research projects supported by the LRI.
6. 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.

Five research areas are selected as main priorities.

#### 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, 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 Research

### 3.1 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; and (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; and (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 Executive

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 2019 call for proposals, the success rate of the first stage (LoI selection) was higher than in preceding years – 20 of the 56 applicants (36%) who submitted an LoI were invited to submit a full proposal (Table 1). In addition, six projects from the previous budget round were invited to submit a revised full proposal, of which four were submitted. This resulted in 24 full proposals. Five full proposals were accepted for funding, four projects focusing on early detection, and one on nerve function impairment and reactions (Figure 1).

**Table 1: Success rate in budget years 2016-2019**

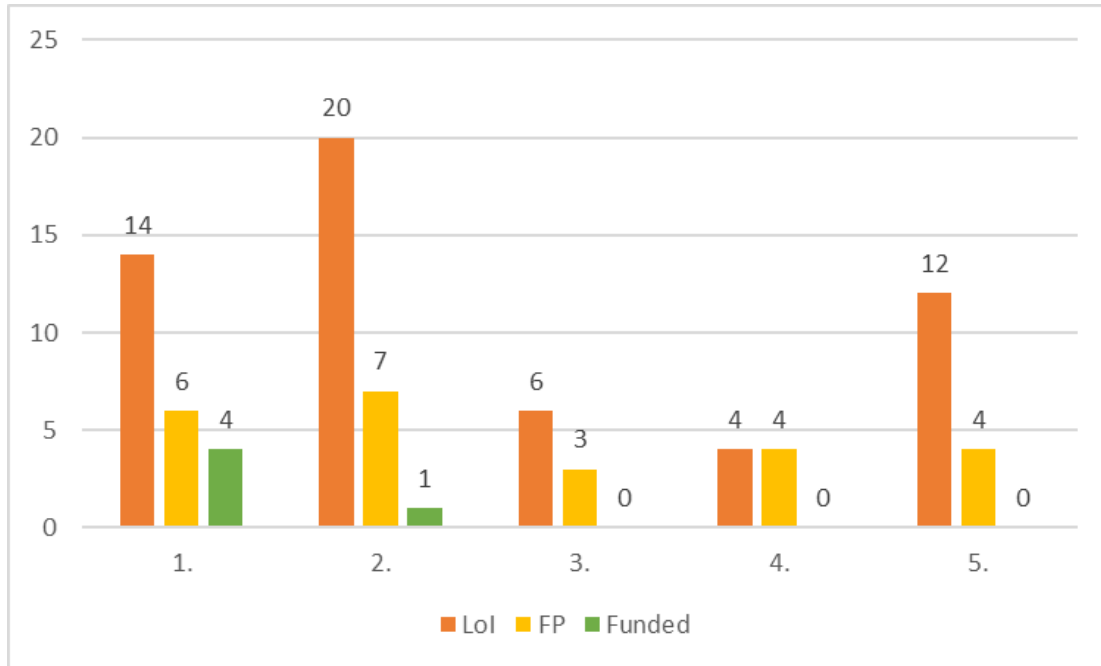
Budget year	Selection of Letter of Intent (LoI)			Selection of Full Proposals (FP)		
	Number	Accepted	Success rate	Number*	Accepted	Success rate
2016	70	15	21%	16	11	69%
2017	40	6	15%	10	4	40%
2018	58	21	36%	20	10	50%
2019	56	20	36%	24	5	21%

*\*In 2016, one applicant from the preceding budget round was invited to skip the LoI phase and re-submit his/her 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.*

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

country. This was similar among applicants submitting a full proposal.

**Figure 1: Number of Letters of Intent and full proposals by research priority in 2019**



LRI research priorities

1. Early detection
2. Nerve function impairment and reactions
3. Inclusion
4. Prevent disability
5. Interrupt transmission



### 3.2 New research projects funded

Four research projects in the research priority area of 'Early detection' were accepted for funding, and one in the area of 'Nerve

function impairment and reaction'. In the other research priority areas, no research projects were accepted.

**Table 2: New projects accepted for funding in budget round 2019**

Research priority	Title Research Project	Lead applicant	Total grant	Focus country
1	Monitoring the effect of prophylactic interventions in contacts of leprosy patients including field-application of a novel immunodiagnostic test in Bangladesh.	Prof. dr JH Richardus, MD, PhD <i>Erasmus MC, University Medical Center Rotterdam, the Netherlands</i> & Prof. dr. A Geluk, PhD <i>Leiden University Medical Center, the Netherlands</i>	€225,000	Bangladesh
1	Assessing the effectiveness of Intensified Extended Contact Survey (IECS) to routine leprosy case detection in Bangladesh.	Dr Aung Kya jai Maug Damien Foundation Bangladesh	€150,333	Bangladesh
1	Collaboration with traditional healers to reduce the delay of leprosy diagnosis and improve detection of hidden leprosy patients in Sierra Leone through establishment of a referral system.	Dr. Lynda Foray <i>National Leprosy and TB control programme; Ministry of Health and Sanitation, Sierra Leone</i>	€193,722	Sierra Leone
1	Integrated approach with skin camp, eSkin Health app, and teledermatology in early detection and effective management of skin NTDs in Côte d'Ivoire.	Dr Rie Roselyne Yotsu <i>School of Tropical Medicine and Global Health Nagasaki University, Japan</i>	€120,000	Côte d'Ivoire
2	Implementation of Dapsone Hypersensitivity Syndrome (DHS) Biomolecular Predictive Test to reduce the incidence of DHS among Leprosy Patients in Papua and Nepal.	Hana Krismawati, MSc. <i>Microbiology Department- Institute of Health Research and Development of Papua, Indonesia</i>	€145,321	Indonesia, Nepal



In addition to the proposals which were granted through the LRI call for proposals – two proposal which were granted through the European and Developing Countries Clinical Trial Partnership (EDCTP) were co-financed by the LRI in 2019. Finally, a leprosy vaccine study was co-financed by the LRI in 2019.

5	Post ExpOsure Prophylaxis for LEprosy in the Comoros and Madagascar (PEOPLE)	Prof. dr B. de Jong <i>Institute of Tropical Medicine, Antwerp, Belgium</i>	€2,999,478 (LRI €200,000)	Comoros, Madagascar
5	Chemoprophylaxis for leprosy: comparing the effectiveness and feasibility of a skin camp intervention to a health centre based intervention.	Dr L. Mieras <i>NLR, the Netherlands</i>	€3,198,356 (LRI €200,000)	Mozambique, Ethiopia, Tanzania
5	Safety trial to transition the defined subunit vaccine, LepVax, into M. leprae-infected individuals in a leprosy-endemic country - Leprosy Vaccine Phase 1b	Mr Darren Schaupp <i>America Leprosy Missions</i>	€350,000	Brazil, USA

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

### 3.2.1 Example project: Early detection

#### Collaboration with traditional healers to reduce the delay of leprosy diagnosis and improve detection of hidden leprosy patients in Sierra Leone through establishment of a referral system

Lead applicant	Dr Lynda Foray
Institute	German Leprosy and TB Relief Association
Country	Sierra Leone
Start date	June 2019
Duration	48 months
Co-funding	-
Budget	€193,723

Sierra Leone belongs to the West African countries, which continue to report leprosy cases. Until now, no studies have been conducted to know the number of people affected by the disease and their distribution within the country. Many of the newly found leprosy patients are seen with deformities and disabilities. This shows that there is a delay in diagnosis and treatment of leprosy in Sierra Leone. Moreover, there are only few cases among children, which points towards a current weakness of the health system to identify, diagnose and treat leprosy patients at an early stage. Traditional healers have a well-trusted position in their communities. Many people in Sierra Leone indicate to first seek help in health care from traditional healers before visiting a health facility. During the Ebola outbreak in the country, traditional healers played a major role in the prevention and control of the infection. This has shown the great potential of working with traditional healers.

Therefore, this project plans to collaborate with traditional healers and to introduce a referral system between them and the health centres for suspected leprosy patients. The objectives are to see, whether this referral system:

1. affects (reduces) the delay of diagnosis in the country;

2. reduces the number of patients found already with disabilities; and
3. finds hidden leprosy patients in the country.

A detailed mapping exercise has been done in order to know the geographical distribution of leprosy patients within the country according to the past five years (2013-2017). Moreover, important characteristics of those patients, for example whether they had already disabilities, were linked to those maps. With these maps, the researchers selected five intervention districts, where they will collaborate with traditional healers, and six comparable control districts, where passive case finding will continue. The project begins with a one-year planning and preparation phase, which involves extensive sensitization and subsequent training with the traditional healers, health facility staff and people affected by leprosy. The aim is to introduce all key components for a successful referral system. Afterwards, a two-year implementation phase begins. All newly diagnosed leprosy patients in the intervention and control districts will be assessed for their delay of diagnosis through the use of a questionnaire at the health centre. This allows evaluating the impact of the referral system with traditional healers on the mentioned objectives in the final project year.

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

#### Implementation of Dapsone Hypersensitivity Syndrome (DHS) Biomolecular Predictive Test to reduce the incidence of DHS among Leprosy Patients in Papua and Nepal.

Lead applicant	Hana Krismawati, MSc.
Institute	Microbiology Department Institute of Health Research and Development of Papua
Country	Indonesia, Nepal
Start date	Tbd
Duration	36 months
Co-funding	Turing Foundation
Budget	€153,321

Dapsone hypersensitivity syndrome (DHS) is a serious and potentially fatal side effect of dapsone treatment. Global estimates vary from 0.5 to 3.6% or more in high risk populations. The case fatality rate among those who do report to a hospital or clinic is around 10% and in 85% of the DHS cases have been associated with the HLA -B\*13:01 allele.

Papua and Mollucas are islands with the largest leprosy population in Indonesia. DHS reportedly occurs in 3% of cases and has a mortality rate of around 10%. A study in Nepal found 2% incidence of DHS after initiating multi drug therapy. DHS has a large impact on the patient's family and on the health care system, requiring hospitalization for weeks or months. Moreover, it increases stigma of leprosy in the community.

This study aims to reduce the incidence of dapsone allergy among leprosy patients in Papua, Mollucas and Nepal by testing the patients blood for the presence of the HLA-B\*13:01 allele before they receive dapsone as part of their MDT.

Patients with a positive test result are at increased risk for developing DHS and they should not take dapsone. Patients with a negative test result have a low risk of developing DHS. However, they should still be careful to note any symptoms over the first 4-6 weeks of treatment and notify the doctor of any changes. This study will assess the use of this test in two different populations at risk for DHS.

### 3.2.3 Example project: Transmission

#### **Chemoprophylaxis for leprosy: comparing the effectiveness and feasibility of a skin camp intervention to a health centre based intervention. An implementation trial in Mozambique, Ethiopia and Tanzania.**

Lead applicant	Dr Liesbeth Mieras
Institute	NLR
Country	The Netherlands
Start date	October 2018 (funded by LRI in 2019)
Duration	48 months
Co-funding	European and Developing Countries Clinical Trial Partnership (EDCTP)
Budget	€200,000 (total grant €3,198,356)

The aim of the implementation trial is to contribute to interrupting the transmission of *M. leprae* by identifying the most effective and feasible method of screening people at risk of developing leprosy and administering chemoprophylaxis in Ethiopia, Mozambique and Tanzania.

The primary objectives are: 1) To compare the effectiveness of a skin camp prophylaxis intervention to a health centre-based prophylaxis intervention in terms of the rate of leprosy patients detected and delay in case detection; 2) To compare the feasibility of the two chemoprophylaxis interventions in terms of cost effectiveness and acceptability.

The objectives will be achieved using a two-arm, cluster-randomized implementation trial design, comparing two interventions for screening of contacts of leprosy patients and distribution of single-dose rifampicin (SDR) as post exposure prophylaxis (PEP).

One arm will be community based, using skin camps to screen around 100 contacts of leprosy patients and provide them with SDR when eligible. The other arm will be health centre-based, inviting household contacts to

be screened and given SDR when eligible. Both interventions will use a common skin diseases approach; other dermatological (skin) diseases, such as common skin diseases and HIV/AIDS or neglected infectious diseases (NIDs) manifesting skin lesions, will also be diagnosed and treated. In this way, the project will contribute to health system strengthening in the area of diagnosis and treatment of dermatological conditions. A mobile phone application called SkinApp, which is developed by the NLR, will be available to help health workers in diagnostic and treatment plan decision making.

This study will translate a medical intervention of proven efficacy (single dose rifampicin, SDR) into routine care. Because of the feasibility component and the development of guidelines as part of the study, the results can be presented for uptake in national and international policies.

The project period is 52 months, of which three years include patient activities. The targeted sample size is 675 new leprosy patients and a total of around 30,000 contacts screened and offered SDR-PEP.

## 4 Capacity building

### 4.1 The LRI Spring Meeting

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 LRI Spring Meeting 2019 lasted two days and had a record of 32 presentations. Like in 2018, R2STOP funded researchers were also invited to present their projects. In total, 76

persons attended the meeting, including representatives of ILEP, the Turing Foundation, the European and Developing Countries Clinical Trial Partners (EDCTP), and Novartis Foundation.

On day two, the Global Partnership for Zero Leprosy (GPZL) presented the process of the research agenda working group. In addition, the LRI presented the results of their stakeholders' consultation on research priorities. In the afternoon four discussion groups were organized around the following topics: (1) diagnostic tests / digital health; (2) PEP / vaccines; (3) operational research / modelling; and (4) stigma / disability.

A report of the meeting was published in *Leprosy Review*:

*Meeting report: the Leprosy Research Initiative Spring Meeting.* *Leprosy Review* (2019) 90, 183-200.





## 4.2 Operational Research Workshop

In 2019, the third Operational Research workshop was organized. The goal of these workshops is to increase the quality of operational research proposals through capacity strengthening workshops, aimed at teaching research methods, including proposal writing, with additional mentoring during the implementation phase.

This year, the workshop was hosted in Nairobi, Kenya. A total of nine research teams applied for participation. After a selection process, eight research teams were invited to participate from six different countries: Nigeria (3), Ethiopia (1), Kenya (1), Tanzania (1), Congo DRC (1) and Niger (1). The workshop resulted in five Letters of Intent submitted for the LRI 2020 budget round.

Topics presented during the workshop included (1) LRI funding opportunities, (2) what is operational research, (3) defining the research question, (4) how to do a literature review and manage references, (5) ethical and regulatory approval, (6) quantitative research overview, (7) the use of questionnaires, (8) qualitative research methods, (9) data and outcome measures, (10) sampling and sample size calculation, and (11) research implementation. The workshop included theoretical support, as well as practical / team work possibilities.

Two of the five teams from the 2018 Operational Research workshop received funding for their proposal in 2019.



### 4.3 PEP workshop

Together with NLR and the Global Partnership for Zero Leprosy (GPZL), the LRI hosted a 4-day workshop in Amsterdam, 5-8 Nov, 2019, to discuss issues related to post-exposure prophylaxis (PEP).

For this workshop, researchers and programmatic partners came together



*Joshua Oraga, IDEA Kenya, discusses the importance of engaging persons affected by leprosy*

to work out common country packages for SDR-PEP implementation and to develop proposal outlines to advance PEP research. The workshop was composed of two distinctive groups, one focusing on research and one on operations.

The operations group developed three specific country profile packages: SDR-PEP start-up; SDR-PEP scale-up; and SDR-PEP last-mile. These profiles will help countries with preparing, implementing and evaluating SDR-PEP into their national programmes.

The research working group initially focused on the four topics in the context of PEP: (1) PEP targeting and delivery; (2) New regimen; (3) Mapping; (4) Modelling and Investment Case. Concrete ideas related to PEP targeting and delivery will be further developed in 2020.

This was the first workshop of its kind organized by GPZL, LRI and NLR. Lessons from this workshop will help organize future workshops.



## 5 Other activities

### 5.1 International Leprosy Conference

The 20<sup>th</sup> International Leprosy Conference took place in place Manila, Philippines from September 9-13, 2019. The three-yearly conference provided opportunity for scientists, researchers, health staff, NGOs and organisations of persons affected by leprosy to interact, discuss and share experiences in a variety of fields.

Research funded by the LRI was well represented with over 30 oral and poster presentations. The LRI was invited to give a plenary talk during the conference with the title "The LRI perspective on leprosy research". In addition, we presented the results of our own stakeholders' consultation on research priorities which we conducted in 2018.

At the LRI booth we provided lists of publications from LRI-funded research, hard copies of the publication of our stakeholders' consultation and an opportunity for people to sign up as external reviewer. There was a lively exchange with numerous visitors at the booth.

The conference also provided a good opportunity to meet face-to-face with the LRI committee members.



## 6 Current and Future perspectives

The call for proposals to be financed under the LRI 2020 budget was published in December 2018. Applications will, for the first time, have to be submitted via the online LRI Application Portal. For this call - proposals addressing any of the five LRI research priorities will be eligible for funding.

Decisions about approvals for the budget 2020 were discussed in the Executives Group meeting of November 2019. These will be reported in the 2020 annual report.

In April 2020, the LRI Spring Meeting is planned to take place in the Netherlands.

The search for additional partners and new co-financiers of LRI approved research

projects will continue in 2020. The need and requests for leprosy-related research still exceed the available budget of the LRI and its present co-financiers.

Collaboration with the Global Partnership for Zero Leprosy in the implementation of the research agenda will continue in 2020, maximizing our joint impact in promoting, facilitating and funding high-quality leprosy research.

## 7 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	CEO, NLR (Chair)
Mr Peter Derrick	CEO, effect:hope
(until September 2019)	
Ms Kim Evans	CEO, effect:hope
(from September 2019)	
Mr Burkard Kömm	CEO, GLRA
Mr Brent Morgan	Director, TLMI
Mr Bill Simmons	President/CEO, ALM

### 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 2019 were:

Dr David Scollard	Retired Director of the National Hansen's Disease Programs (Chair)
Dr Wim H. van Brakel	Medical Director, NLR (Secretary)
Dr Peter Steinmann	Project Leader, Swiss Tropical and Public Health Institute; Chair SRC R2Stop
Dr Christa Kasang	Research Coordinator, GLRA
Mrs Jannine Ebenso	Head of Quality Assurance, TLMI
Dr Paul R. Saunderson	Medical Director, ALM

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 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 2019 were:

<p>Prof. Dr William R. Faber (Chair) (until April 2019)</p>	<p>Emeritus Professor of Tropical Dermatology, Academic Medical Centre, University of Amsterdam, the Netherlands</p>
<p>Dr R.W. Truman (Chair) (from October 2019)</p>	<p>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.</p>
<p>Dr Jos H.M. Dekker</p>	<p>Rehabilitation Physician, Heliomare Rehabilitation Centre at Red Cross Hospital, the Netherlands</p>
<p>Dr Gigi J. Ebenezer</p>	<p>Associate Professor, Neurology Department, Johns Hopkins School of Medicine, USA</p>
<p>Dr Bassey E. Ebenso</p>	<p>Research Fellow, Leeds University, Institute of Health Science, United Kingdom</p>
<p>Prof. Dr Victor P.M.G. Rutten</p>	<p>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</p>
<p>Prof. Dr Maria Leide W.R de Oliveira</p>	<p>Professor of Dermatology, Federal University of Rio de Janeiro, Brazil</p>
<p>Prof. Dr Tjip S. van der Werf (until April 2019)</p>	<p>Pulmonologist, Head of the Infectious diseases service Tuberculosis unit, University Medical Centre Groningen, the Netherlands</p>
<p>Prof. Dr Françoise Portaels (from October 2019)</p>	<p>Professor Emeritus, Institute of Tropical Medicine Antwerp Belgium</p>

### **Office team**

Ms Nicole Dinnissen	Programme Officer
Dr Nienke Veldhuijzen	Technical Officer
Ms Linda van den Berg	Secretary

## 8 Financial paragraph

### Summary Budget Stichting Leprosy Research Initiative (LRI) 2020

Amounts in Euro

Main Group	Budget 2020
<b><u>Income:</u></b>	
- Income from contributors	1,090,000
- Income for co-financed projects	395,000
<b>Sum of income</b>	<b>1,485,000</b>
<b><u>Expenses:</u></b>	
-Research project costs	1,332,000
-Running costs (via NLR) and other operating expenses	243,000
<b>Sum of expenses</b>	<b>1,575,000</b>
<b>Result</b>	<b>(90,000)</b>

*Please refer to the annual accounts of LRI for the detailed budget of 2020.*

### Financial results 2019

In 2019 the LRI received a total contribution from partners of €1,104,141 and in addition to this an amount of €97,410 was received from other income from the Turing Foundation and ILEP partners. The total expenses arrived at €1,406,595. The negative result of 2019 amounting to €205,045 is deducted from the earmarked reserves of the LRI. This decreased the total earmarked reserves from €837,357 to €632,312. The earmarked reserves are formed in accordance with the LRI policy, please refer to the notes accompanying the annual account for 2019 for the LRI policy.

The freely available funds, consist of cash held in the bank account as per 31 December 2019 and amounts to €1,067,588.

### Outlook 2020

LRI will receive a contribution of €1,090,000 from partners and an amount of €395,000 for co-financed projects. The expected expenditures will be €1,575,000. Please refer to the year plan of the LRI published on the website for the detailed budget and a detailed description of the activities in 2020.

**Annual Accounts 2019**  
***Jaarrekening 2019***  
**Stichting Leprosy Research Initiative**  
Amsterdam, The Netherlands

## Contents

	Page
<b>I:</b> Balance sheet as per December 31, 2019	23
<b>II:</b> Statement of Income and Expenses 2019	24
<b>III:</b> Notes accompanying the annual account for 2019	
<b>a.</b> General and accounting policies	25
<b>b.</b> Notes to the Balance sheet 2019	27
<b>c.</b> Notes to the Statement of Income and Expenses 2019	30
<b>IV:</b> Other information	
Independent auditor's report	32
<i>Annexes:</i> annex 1: Overview of research projects with budget comparison	33
annex 2: Budget 2020	34
annex 3: Multi Annual Budget 2020-2022	35
annex 4: Management Board and Executives Group	36



## I. Balance sheet as at 31 December 2019

Amounts in Euros

	Notes	31-dec-19	31-dec-18
<b>ASSETS</b>			
<i>Fixed assets</i>			
Tangible fixed assets	1.	€ 0	€ 0
		€ 0	€ 0
<i>Current assets</i>			
Accounts receivable	2.	€ 4,233	€ 1,474
Contributions due		€ 85,696	€ 174,735
Paid in advance		€ 44,789	€ 79,060
Cash and cash equivalents		€ 1,067,588	€ 736,447
		€ 1,202,305	€ 991,717
<b>Total assets</b>		€ 1,202,305	€ 991,717
<b>LIABILITIES</b>			
<i>Reserves</i>			
Continuity reserves	3.	€ 0	€ 0
Earmarked reserves		€ 632,312	€ 837,357
		€ 632,312	€ 837,357
<i>Short-term liabilities</i>			
Accounts payable	4.	€ 424,799	€ 98,406
Deposits		€ 12,298	€ 0
Balances and accounts to NLR		€ 132,896	€ 55,952
		€ 1,202,305	€ 991,717
<b>Total liabilities</b>		€ 1,202,305	€ 991,717

II. Statement of Income and Expenses for the year 2019

Amounts in Euros

	Notes	Realisation 2019	Budget 2019	Realisation 2018
<b>INCOME:</b>	5.			
Income from allied and joint non-profit organisations	€	1,104,141	€ 1,215,000	€ 1,107,492
Other income	€	97,410	€ 20,000	€ 20,118
<b>Total income</b>	€	<b>1,201,550</b>	€ <b>1,235,000</b>	€ <b>1,127,610</b>
<b>EXPENSES:</b>	6.			
Research project costs	€	1,184,432	€ 1,416,000	€ 588,848
Staff costs, housing and office costs	€	192,461	€ 185,000	€ 198,086
Other operating expenses	€	29,703	€ 31,000	€ 52,667
<b>Total expenses</b>	€	<b>1,406,595</b>	€ <b>1,632,000</b>	€ <b>839,602</b>
<b>Result of income and expenses</b>	€	<b>-205,045</b>	€ <b>-397,000</b>	€ <b>288,008</b>

### **III. Notes accompanying the annual account for 2019**

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

This is the annual account of 2019 of LRI (Stichting Leprosy Research Initiative). The LRI has been registered since June 1st 2015 as a Foundation under Dutch law. The LRI has taken over all activities from the 1st of January of 2015 from NLR and this are annual accounts of the LRI presented for the year 2019, started on the 1st of January and ended December 31st. The LRI is registered under 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**

The LRI has all its work proceedings and activities fully delegated to NLR. NLR runs the 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 the LRI is Wibautstraat 137k, 1097 DN in Amsterdam, Netherlands.

#### **Accounting period**

The annual accounts have been drawn up by reference 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 2019 (approved by the Supervisory Board of NLR in December 2018).

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 the LRI research fund and contributes an equal share to the 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 a actual cost basis. The income is shown gross, before any deduction of associated costs, unless otherwise is stated. Necessary costs to realise certain benefits, are presented in the statement of income and expenses as expense.

**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 represents the balance of the bank account held for head office of the 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 was received for a specific research project than needed in that particular year for that project, the 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, we will deposit the money in the general joint fund or refund this to the contributor. The reserves is the result of income and expenses and is held in accordance with budgets for (scientific) research and running costs of the LRI for future years to ensure sustainability of the 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 2019 is added to the earmarked reserves. The earmarked reserve consists of reserves set aside for future funding of LRI projects. The LRI holds no investments.

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

As a Foundation the LRI is managed by the director of Netherlands Leprosy Relief (NLR), implementing the decisions of the LRI Executive Group and supervised by the Supervisory Board of NLR. No remuneratrion was paid to the Supervisory Board members and Director of NLR, and no loans, advances or guarantees were given. In 2019 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 2019 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 2019

#### 1. Tangible fixed assets

Tangible fixed assets are used for the main activities and entirely held for operational management. The LRI holds no tangible fixed assets and therefore this is not valued in 2019. Also in 2018 no tangible fixed assets were required.

#### 2. Receivables

All receivables are due within one year.

	<b>31 December 2019</b>	<b>31 December 2018</b>
	in €	in €
Contributions and amounts due	89,929	174,735
Paid in advance	44,789	79,060
Cash and cash equivalents	<u>1,067,588</u>	<u>736,447</u>
	<u><b>1,202,305</b></u>	<u><b>990,242</b></u>

The income from contributions are accounted for once the commitment has been confirmed. The item contributions and amounts due relates to the contribution of NLR and effect:hope towards the ALM LepVax research project, this amount is expected but not yet received income. Also an amount of € 36,000 from a LRI partner was taken under this item which is expected but not yet received income for 2019. This amount is received in January 2020.

The paid in advance amounts, also prepayments, which are already effectuated in 2019, are payments to research institutes and universities for activities in the first quarter of 2019.

Cash and cash equivalents are cash and bank balances in Euros in the Netherlands held by the LRI office in Amsterdam. LRI holds its main current account at ING Bank (NL). The balance of cash and cash equivalents is immediately available. The cash and cash equivalents balance for the year ended 31 December 2019 is € 1,067,588.

#### 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 the LRI for future years to ensure sustainability of the LRI so that its projects proceedings and ongoing activities are not affected and also to grant new research project proposals.

	<b>31 December 2019</b>	<b>31 December 2018</b>
	in €	in €
Earmarked reserves	<u>632,312</u>	<u>837,357</u>
	<u><b>632,312</b></u>	<u><b>837,357</b></u>

#### General notes on the reserves

- A deficit of nearly € 400,000 was budgeted for the year 2019. The negative result of 2019 arrived at € 205,045 and is withdrawn from the earmarked reserves of LRI. Detailed cash flow planning introduced in 2020 will ensure sufficient liquidity for the the 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, the LRI will allocate this money to the same project in the following year. From the total amounts received in 2019, a few partners contributed to specific research projects which remained unspent in 2019. The majority of these funds has been allocated to activities in 2019. These consist of financing the current projects, award new research projects and a proportional part for financing the LRI organisation.

- LRI holds no continuity reserve.

The LRI's reserves are as follows:

	Continuity reserves	Earmarked reserves	Total
	in €	in €	in €
Balance as per 1 January 2019	0	837,357	837,357
- Movements	0	0	0
- Withdrawals and additions	0	(205,045)	(205,045)
Balance as per 31 December 2019	<b>0</b>	<b>632,312</b>	<b>632,312</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 2019	31 December 2018
	in €	in €
Accounts payable/creditors	<u>424,799</u>	<u>98,406</u>
	<b><u>424,799</u></b>	<b><u>98,406</u></b>

Accounts payable are mainly amounts payable to the amount of € 255,000 for (scientific) research in 2019, 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 the LRI. The amounts received in advance (€ 160,000) are also calculated under this item, which are unspent funds from Turing Foundation towards research projects.

##### Deposit

	31 December 2019	31 December 2018
	in €	in €
Deposit/Funds to be returned	<u>12,298</u>	<u>0</u>
	<b><u>12,298</u></b>	<b><u>0</u></b>

An amount of € 12,298 is deposited to guarantee unspent funds for research projects that has ended will be returned to a Co-Financing partner as agreed upon allocation letter. This amount will be settled in the first half year of 2020.

##### Balances and accounts to NLR

	31 December 2019	31 December 2018
	in €	in €
	<u>132,896</u>	<u>55,952</u>
	<b><u>132,896</u></b>	<b><u>55,952</u></b>

The amount of € 132,896 reflects to the debt LRI has towards NLR. This amount has been settled in 2020.

**Commitments not included in the balance sheet**

LRI has made commitments for 2020 and beyond for running research projects for a total value of € 1,068,803.

**Events after balance sheet date**

COVID-19 response measures have impacted the Dutch society. LRI is also confronted with the consequences. The response measures might affect the realisation of the budget for the year 2020. 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 2019 and the continuity of the LRI.



### III c. Notes to the Statement of Income and Expenses 2019

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 the LRI running costs. In 2019 the current partners are: NLR, American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief Association (GLRA/DAHAW), effect:hope (The Leprosy Mission Canada) and The Leprosy Mission International (TLM). The Mission to End Leprosy (TLM Ireland) supports the running costs of the LRI. The breakdown of the total income is as follows:

	Realisation 2019	Budget 2019	Realisation 2018
	in €	in €	in €
Income from allied and joint non- profit organisations	273,798	374,000	272,800
effect:hope	137,743	134,000	132,800
GLRA/DAHAW	183,800	184,000	182,800
TLM International	133,800	134,000	132,800
The Mission to End Leprosy	0	20,000	20,000
NLR	350,000	350,000	350,000
Action Damien	25,000	0	0
Other income	10,762	20,000	17,848
Others	86,648	20,000	18,562
	<u><b>1,201,550</b></u>	<u><b>1,235,000</b></u>	<u><b>1,127,610</b></u>

The total amount available for allocation in line with the objectives for 2019 arrived at: € 1,201,550.

The realisation of the total income in 2019 was slightly lower than the drawn up budget. From the Turing Foundation we received a contribution for the running costs of the LRI to the amount of € 10,762. 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 2019. The amount under other income from others consists of funds from ILEP partners towards an ALM hosted research project. This amount covers the deficit in income from ALM and is agreed to be funded via contributions of the other ILEP partners towards this project.

#### 6. Expenses

The expenses mainly involves the funding of (scientific) research project costs. A total of 33 research projects have been funded in 2019 and in the meantime 12 of these projects are completed in 2019. In 2019 the LRI initiated also a Spring Meeting which is held annually and different workshops. Please refer to the overview of research costs on page 11 for the specification of the project expenses. The LRI has spent a total of € 1,406,595 (2018: € 839,602) on research funding and running costs.

	Realisation 2019	Budget 2019	Realisation 2018
	in €	in €	in €
<i>Research</i>			
- Research projects funding	1,184,432	1,838,000	588,848
	<u><b>1,184,432</b></u>	<u><b>1,838,000</b></u>	<u><b>588,848</b></u>

The actual research project costs were 36% lower than budgeted due to the fact that most of the new LRI projects started their activities around the half of 2019. However the budgets for the research projects are year budgets and also allocated yearly, and from the moment a proposal is granted the project should start within six months. The research project overview on page 11 specifies the granted funds per (scientific) research project.

The executive institutions of 4 out of 33 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. The LRI has approved the requests of the grantees in accordance with the LRI policy, allowing the completion of the projects in 2020. Therefore final payment for these projects in 2019 is postponed and will take place in 2020 upon completion of the project.

Including the amount co-financed by Turing Foundation and ILEP partners the total budget allocated under the LRI policy in 2019 sums up to € 1,837,678.

	<b>Realisation 2019</b>	<b>Budget 2019</b>	<b>Realisation 2018</b>
	in €	in €	in €
<i>Running costs</i>			
- Staff, housing and office costs	192,461	185,000	198,086
- Other operating expenses	29,703	31,000	52,667
	<u><b>222,164</b></u>	<u><b>216,000</b></u>	<u><b>250,753</b></u>

LRI has no staff members, all staff is employed by NLR. Due to this fact, NLR runs the 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 € 168,416 and other charged support costs for the LRI secretariat officers to the amount of € 24,045. These costs are reimbursed to NLR. In 2019 on average equivalents 2.1 fte (2018: 1.8) were employed via NLR in the LRI secretariat in Amsterdam. The LRI has no staff employed abroad during 2019. For the LRI officers the NLR standard terms, benefits and conditions of employment apply.

In 2019 the total running costs were 3% higher than budgetted mainly due to reservations for holiday allowances (to be paid out in May 2020) and paid leave days.

The staff costs for the LRI officers arrived at € 168,416 and can be specified as follows:

	<b>Realisation 2019</b>	<b>Budget 2019</b>	<b>Realisation 2018</b>
	in €	in €	in €
Wages and salaries	128,634	119,000	127,940
Social security costs	21,162	18,000	19,965
Pension contributions	12,991	13,000	14,136
Other personnel costs	5,629	5,000	4,925
	<u><b>168,416</b></u>	<u><b>155,000</b></u>	<u><b>166,967</b></u>

Number of LRI employees on Dec. 31	3	3	3
------------------------------------	---	---	---

In addition to these staff costs for the 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 € 24,045 in 2019 (2018: € 39,119). The total staff costs of the LRI amount to 168,416. This was 9% higher than budgetted.

The Director of NLR and the Supervisory Board of the NLR and the Executive Group of the LRI, do their work on a voluntary basis and do not receive any remuneration for their activities.

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 2019 included in the annual report

#### Our opinion

We have audited the financial statements 2019 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 2019 and of its result for 2019 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 2019;
2. the statement of income and expenses for 2019; 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.

Oranje Nassaulaan 1  
1075 AH Amsterdam  
Postbus 53028  
1007 RA Amsterdam

Telefoon 020 571 23 45  
E-mail [info@dubois.nl](mailto:info@dubois.nl)  
[www.dubois.nl](http://www.dubois.nl)  
KvK nummer 34374865



## **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 other information that consists of:

- the Management Board's report;
- other information;
- annexes.

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, 15 July 2020

Dubois & Co. Registeraccountants

A.P. Buteijn RA

**annex 1 Overview of research projects with budget comparison 2019**

Amounts in Euros

Project number		Budget 2019	Realisation 2019*)
<b>1. Current research projects</b>			
703.15.01	INF/Delays in diagnosis & treatment	9,990	8,751
703.15.05	IDRI/Integration of rapid diagnostic tests to facilitate case management of leprosy	39,000	15,432
703.15.07	EUR/Field evaluation of novel immunodiagn. Tools	149,500	149,461
703.15.43	HSRA/Internat.collaboration for translation of Mleprae MVA	21,291	0
703.15.45	FIOCRUZ/Evaluation of the qPCR in household contact monitoring	6,026	2,665
703.15.41	TLM Nepal/Helminth influences in leprosy	39,942	19,942
704.16.31	PUCP/Comparative sequencing, Brasil	5,236	896
704.16.43	IDEA/UN Guidelines Regarding Leprosy and Human Rights, US	4,998	5,446
704.16.47	NLR Indonesia/Promoting inclusive & enabling environments, Indonesia	0	12,490
704.16.57	SIH-R & LC/To identify Mycobacterium leprae, India	19,459	0
704.16.59	MSU/Biomarkers for early detection of leprosy, India/US	23,554	7,660
704.16.71	ENLIST MTX - two randomised controlled trials in ENL	207,162	0
705.17.07	LWM/Inflamed Skin Lesions Along an Area of a Peripheral Nerve, Philippines	30,107	30,107
705.17.30	ENAPAL/Family-based approaches self-management of disab. due to leprosy, podocniosis and LF/Ethiopia	48,628	22,900
705.17.41	SIH-R & LC/Mobile Technology (M-Health) India	8,394	5,586
706.18.28	Enablement/Leprosy and Religion in Nigeria: the role of Churches and Mosques in stigma reduction	20,343	19,884
706.18.39	PUCPR/Functional analysis of candidate variants in the early-onset leprosy phenotype using novel cellular model	21,720	7,240
706.18.46	FUSM/ILEP Promoting inclusion where it matters most: Building resilience in individuals and families, Brazil/India	16,288	12,216
706.18.20	VU Amsterdam/Intersectionality of inclusion	14,000	13,900
706.18.24	TLMB - Factors affecting migration, self-reporting and registration as leprosy cases, Bangladesh	16,007	12,516
706.18.29	SIHR&LC/Design a customized offloading devices to promote healing of plantar ulcers – India	23,461	19,996
706.18.45	Athena Institute/A qualitative and participatory research to improve the management of ENL – Indonesia/India	43,392	37,052
706.18.49	GLRA Uganda - Promoting inclusion of people affected by Leprosy and LF in generic community development	15,553	11,990
706.18.52	FAIRMED/Integrated strategy for early detection of leprosy and other NTDs, Cameroon	46,839	23,420
706.18.57	EUSM/Describing metabolic profiles in leprosy and its morbidities using plasma metabolomics, Brazil	33,389	33,388
707.19.57	PEOPLE	200,000	200,000
707.19.58	PEP4LEP	200,000	200,000
707.19.02	Erasmus MC/Monitoring effect of prophylactic interventions, Bangladesh	75,000	18,750
707.19.20	IRDBP/Implementation of Dapsone Hypersensitivity Syndrome, Indonesia/Nepal	66,226	0
707.19.45	DF/Assessing the effectiveness of IECs, Bangladesh	39,500	0
707.19.60	NLTB/Collaboration traditional healers, Sierra Leone	62,855	61,805
707.19.62	NCGM/Integrated approach skin camp, eSkin Health app, Côte d'Ivoire	41,318	26,354
707.19.04	ALM/LepVax	170,000	85,000
707.19.91	ILC 2019 Manila	3,000	3,796
707.19.92	Internship	1,500	0
707.19.98	PEP Workshop	0	16,110
707.19.99	Workshop Operational Research Kenya	39,000	34,821
709.00.20	SRC/LRI spring & autumn meetings	75,000	64,858
<b>Total research costs for current projects</b>		<b>1,837,678</b>	<b>1,184,432</b>
<b>2. Running costs (staff, housing and office costs)</b>		<b>185,000</b>	<b>192,461</b>
<b>3. Other operating expenses</b>		<b>31,000</b>	<b>29,703</b>
<b>SUBTOTAL</b>		<b>2,053,678</b>	<b>1,406,595</b>
<b>TOTAL</b>		<b>2,053,678</b>	<b>1,406,595</b>

The total amount for 2019 towards projects was budgetted to €2,053,678. This amount consist of € 421,853 co-funding finances from the Turing Foundation and ILEP partners.

\*) This overview shows the actual project costs after deduction of co-funding contribution as of € 151,858 from the Turing Foundation and from ILEP partners € 51,578.

**Budget Stichting Leprosy Research Initiative (LRI) 2020**

Amounts x €1,000/ in Euro thousands

Main Group	Specification	Budget 2020	Realisation 2019	Budget 2019
<b><u>Income:</u></b>				
- Income from contributors *)	ALM	130	274	374
	Damien Foundation	135	25	20
	effect:hope	135	138	134
	GLRA/DAHW	185	184	184
	TLM International	135	134	134
	The Mission to End Leprosy	20	0	20
	NLR	350	350	350
- Other income	Turing Foundation	15	11	20
	Income for co-financed projects	380	86	0
<b>Sum of income</b>		<b>1,485</b>	<b>1,202</b>	<b>1,235</b>
<b><u>Expenses:</u></b>				
<b>Expenses on the Objectives:</b>				
- Research an cofinanced project costs		1,332	1,184	1,416
	<b>TOTAL RESEARCH PROJECTS BUDGET</b>	1,332	1,184	1,416
		<b>1,332</b>	<b>1,184</b>	<b>1,416</b>
-Running costs (via NLR) and other operating expenses		243	222	216
		<b>243</b>	<b>222</b>	<b>216</b>
<b>Sum of expenses</b>		<b>1,575</b>	<b>1,407</b>	<b>1,632</b>
<b>Result</b>		<b>(90)</b>	<b>(205)</b>	<b>(397)</b>
<b>Accumulated joint fund balance 2019</b>			<b>288</b>	
<b>Accumulated joint fund balance 2020</b>			<b>(205)</b>	

\*) Turing Foundation has cofinanced a total of € 151,858 to research projects in 2019 (2019: € 342,477). The total allocated funding, including cofinancing by Turing Foundation via the LRI is € 1,837,678 in 2019 (2018: € 1,165,157).



annex 3

**Multi Annual Budget Stichting Leprosy Research Initiative (LRI) 2020-2022**

Amounts x €1,000/ in Euro thousands

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

	<b>Budget 2020</b>	<b>Projection 2021</b>	<b>Projection 2022</b>
<b>Income:</b>			
Income from contributors	1,090	1,090	1,090
Income for co-financed projects	395	300	244
<b>Sum of income</b>	<b>1,485</b>	<b>1,390</b>	<b>1,334</b>
<b>Expenses:</b>			
<b>Expenses on the Objectives:</b>			
- Approved Leprosy research projects (ongoing)	942	959	662
- Funding of new research projects	390	145	109
	<b>1,332</b>	<b>1,104</b>	<b>771</b>
<b>Running costs</b>	<b>243</b>	<b>243</b>	<b>243</b>
	<b>243</b>	<b>243</b>	<b>243</b>
<b>Sum of expenses</b>	<b>1,575</b>	<b>1,347</b>	<b>1,014</b>
<b>Result</b>	<b>(90)</b>	<b>43</b>	<b>321</b>
	=====	=====	=====

**annex 4**

**Leprosy Research Initiative (LRI)**

**Management Board**

**From**

NLR

1-6-2015

**Executives Group**

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

Mr B. Simmons  
President/Chief Executive Officer; American Leprosy Missions

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

Mr P. Derrick  
Chief Executive Officer; effect:hope (until September 2019)

Ms K. Evans  
Chief Executive Officer; effect:hope (from September 2019)

Mr B. Morgan  
Director; The Leprosy Mission International

Mr J. van Berkel  
Director; NLR (Chair)