THE LEPROSY MISSION GLOBAL RESEARCH
ADDRESSING CURRENT CHALLENGES
SDG 3.3

ZERO TRANSMISSION
- understanding and reducing transmission
- understanding and enabling early diagnosis (including early diagnostic tests)
- monitoring relapse and leprosy drug resistance

GOAL Earlier detection and treatment of new leprosy cases and strategies and trials to stop transmission

ZERO DISABILITY
- early detection and clinical trials for leprosy reactions and nerve damage
- improving reconstructive surgery
- innovating in ulcer care
- enhancing eye care
- strengthening inner wellbeing and mental healthcare

GOAL Reduced disability and transforming physical, mental, emotional and spiritual wellbeing

ZERO DISCRIMINATION
- reducing stigma
- engaging in community-based rehabilitation

GOAL Greater inclusion and justice and people affected by leprosy confidently standing up for their rights
**WHO WE ARE**

We are the world’s largest leprosy-focused organisation; a key player in the fight against leprosy. Our Members from 30 countries work with people of all faiths and none to defeat leprosy and transform the lives of those affected. We work in partnership with governments, universities, local churches, people affected by leprosy and other stakeholders to achieve our vision.

Leprosy can affect anyone regardless of age, gender, nationality, class or religion. However, its severest impact is on people who are marginalised or living in poverty. It is these people, so often stigmatised and left dealing with disability, that we seek to serve.

As well as providing holistic treatment and care for people living with the effects of leprosy in 18 countries across Asia, Africa and the Pacific, we serve future generations so that they will be born into a world free from the oppression of this disease.

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**OUR LEPROSY RESEARCH**

To defeat this disease in our lifetime, we need to invest in research to develop new tools in the fight against leprosy; and we have a proven track record.

The Leprosy Mission has been involved in research for more than 50 years from the testing of anti-leprosy drugs such as clofazimine in the 1960s and 1970s to the innovative surgical procedures pioneered by Dr Paul Brand.

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**CURRENT RESEARCH FOCUS**

Our current research is focused on:

- understanding and reducing transmission
- understanding and enabling earlier diagnosis (including early diagnostic tests)
- monitoring relapse and leprosy drug resistance
- early detection and clinical trials for leprosy reactions and nerve damage
- improving reconstructive surgery
- innovating in ulcer care
- enhancing eye care
- strengthening inner wellbeing and mental healthcare
- reducing stigma
- engaging in community-based rehabilitation

**NEGLECTED TROPICAL DISEASES**

Leprosy is one of the ten NTDs referred to in the 2012 London Declaration. Therefore, in addition to researching leprosy-specific approaches, we are implementing cross-NTDs research. Examples include the treatment and prevention of leprosy and Buruli ulcers, comorbidity of leprosy and soil-transmitted helminths and developing effective approaches to improving mental health in people with NTDs.

**GLOBAL FELLOWSHIP FOR ZERO LEPROSY**

We are working with members of the Global Partnership for Zero Leprosy to share learning and research.
Until recently, there was no proven method to reduce leprosy transmission. Although contact screening is effective, people affected by leprosy can be hesitant to reveal their diagnosis to others, especially where stigma is prevalent.

In 2002, TLMI Bangladesh partnered with Erasmus University in the Netherlands to perform studies which combined contact screening with a single dose of rifampicin; one of the antibiotics used to treat leprosy. This type of drug treatment is called Leprosy Post-Exposure Prophylaxis (disease prevention) or LPEP.

After two years of follow-up, results showed that 57% of contacts had a combined lowered risk for developing leprosy sustained for four years afterwards.

However, people with least contact received greater protection and those with the highest level of contact, such as with household blood relatives, received less protection.

In addition, there was an important trend observed when health staff had LPEP in hand.

Leprosy patients were more likely to permit access to their household and other contacts for leprosy screening; and contacts were more receptive to treatment and learning about leprosy. This access enabled focused efforts for reducing stigma and discrimination.

By 2016, similar LPEP initiatives had been test launched with government health programmes in select districts of Indonesia, India, Nepal, Myanmar, Tanzania, Sri Lanka, Brazil and Cambodia.

In 2018, the WHO issued its updated Guidelines for Diagnosis, Treatment and Prevention of Leprosy, in which it cited TLMI Bangladesh’s collaborative studies as part of the evidence-base for recommending contact screening with LPEP, as global policy for the prevention of leprosy and the reduction of its transmission.

TLMI Trust India is a global leader in transmission studies in relation to the environment, to patients and households and to drug resistance. Since 2016, TLMI Trust India has published 18 papers relevant to transmission and was first to publish rifampicin resistant patient cases.

TLMI Trust India has improved PCR (DNA detection) tests by making the test sensitive for three gene sites instead of one. This means increased sensitivity when the test is used with slit skin smear, blood, nasal and saliva samples.

In 2019, TLMI Trust India published field evidence confirming that leprosy bacteria can be associated with common amoeba found in soil; a single cell host potentially linked to persistence in environmental transmission.

The Leprosy Mission is seeking additional funding to help scale up its LPEP programme.
Leprosy remains difficult to diagnose before symptoms start to appear, and these undetectable missing millions make it hard to stop transmission. An early diagnosis can reduce the risks that lead to permanent physical problems: leprosy inflammatory reactions, nerve damage and disability development.

Dr Annemieke Geluk and her team at Leiden University Medical Centre in the Netherlands have developed field-friendly tools for early diagnosis of leprosy and reactions, partnering with global leprosy research field sites, including African countries, TLMI Bangladesh and TLM Nepal.

Their finger-prick blood test can detect multiple biomarkers that have been released into the blood stream by the body’s immune response to leprosy exposure or infection. The different combinations create biomarker signatures that have the potential to differentiate between people exposed to leprosy, people with paucibacillary or multibacillary leprosy, and people at risk of developing inflammatory episodes.

Studies continue at TLM Nepal and TLMI Bangladesh to identify the best combination of biomarkers to maximise the application of global leprosy diagnostics.

30–50% of leprosy patients develop one or more inflammatory episodes, known as leprosy reactions, before, during or even years after multidrug therapy. Most reactions start within five years of leprosy diagnosis and can persist for many years.

Leprosy reactions are the primary cause of nerve damage and disability development. Many patients require repeated hospitalisation and long-term medical treatment before episodes cease. At any one time, 10–30% of leprosy hospital beds are occupied by reaction patients. Doctors have limited options for treating reaction patients, and no single drug completely stops nerve damage. Reactions can be long-term and the drugs can have serious side effects such as diabetes, blindness, fractures and joint issues. Due to a combination of stigma, duration of stay and poverty, leprosy patients can rarely find anywhere else for treatment.

TLM Trust India and TLM Nepal have performed studies that highlight how reactions affect households; casting families into catastrophic economic failure.

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TOWARDS ZERO LEPROSY DISABILITY

ENLIST is spearheaded by Dr Steve Walker and Dr Diana Lockwood of the London School of Hygiene and Tropical Medicine. In the quest for steroid sparing drugs, LSHTM also partnered with TLM Trust India in a clinical trial using azathioprine to treat type 1 reactions and neuritis. This AZALEP study was conducted at four hospital sites.

The world class facilities of The Leprosy Mission and the number of people affected by leprosy which are served, provides a unique opportunity for researchers to collaborate in the global fight against leprosy.

PROFESSOR DIANA LOCKWOOD BSC, MD, FRCP, PROFESSOR OF TROPICAL MEDICINE, LSHTM

A further collaboration between Dr Annemieke Geluk and TLM Nepal has identified evidence that urine contains biomarkers that may lead to the development of early diagnostic tests for reactions.

TLM Nepal is undertaking a clinical trial with a new drug for treating erythema nodosum leprosum and has published studies that have linked intestinal worm infections with the development of leprosy reactions.

30–50% LEPROSY PATIENTS DEVELOP AT LEAST ONE LEPROSY REACTION
Leprosy can cause permanent peripheral nerve damage with devastating consequences, leaving eyes, hands or feet without motor movement or pain sensation. While in some patients, damaged nerves can generate feelings of constant pain. Those who lack pain, however, are at high risk for the development of pressure ulcers which can lead to severe tissue damage. Recurrent ulcers can lead to disability and amputation.

Self-care is critical in this context but putting it into practice may be challenging. Daily physical labour or walking long distances may be a necessary fact of life to provide for a family with few or no other options.

Approximately 20% of leprosy patients are at risk of developing ulcers. On average, people affected by leprosy develop their first ulcer four to five years after diagnosis. After their first ulcer, a patient is at high risk for recurrence, which can eventually lead to amputation.

50–90% or more leprosy hospital beds are in continual use by patients with ulcers. 80% of these patients have foot ulcers. The average hospital stay can last five to six weeks and up to ten or more months.

A person affected by leprosy may experience a downward spiral of losses; their employment, their limbs and their home. Very often, they are abandoned by their family.

In early 2018, TLM Nepal began a study using a new technique for healing ulcers called Leukocyte Platelet Rich Fibrin (L-PRF). The patient’s blood samples are collected and spun in a centrifuge to separate and concentrate the white blood cells and growth factors. The separated cells and growth factors are applied directly to the debrided wound which then heals more rapidly than conventional ulcer treatment.

TLM Nepal, TLM Trust India and TLM Nigeria are collaborating on a research project to further investigate and improve leprosy ulcer care.

In 2016, surgeons from TLM Trust India and TLM Nepal served as part of an expert group to publish a Protocol for a Randomised Controlled Trial Investigating Decompression for Leprous Neuropathy *

TLM Trust India is improving standardised methods in reconstructive surgery to repair hand contractures with faster recovery rates and advanced techniques to correct grip weakness.

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Although the prevention, diagnosis and treatment of leprosy are vital in stopping this disease, no strategy or holistic approach will succeed while leprosy stigma and discrimination still exist.

Since 2016, TLM Trust India and TLMI Bangladesh have performed 22 research studies on discrimination with topics including:

- access to disability entitlements;
- empowerment through adult literacy;
- inclusive education for disabled children;
- social participation;
- stakeholders’ perceptions;
- healthcare providers’ perceptions and participation;
- development of the Child Attitude Towards Illness Scale (CATIS) to measure children’s and adolescent’s attitudes towards leprosy

These studies not only highlight the continued need for such initiatives but provide evidence-based solutions that policy makers can adopt at a national and international level.

TLM Trust India’s CREATE project (Civil Society Organisations for Resource Mobilisation, Empowerment, Advocacy, Training and Employment) developed a stigma tool kit that can be used in any stigmatising disease with minimal modifications.

Funded by the Leprosy Research Initiative (LRI), TLM Niger, IDEA Niger, AIFO Mozambique, IDEA Mozambique and IDEA Nigeria are researching the development and use of participatory methods for people affected by leprosy to understand their rights and increase dignity and inclusion in their communities.

Also funded by LRI, TLM Nigeria, the University of Jos and the not-for-profit company, Enablement Ltd, are studying how faith groups can affect perception to leprosy.

Hawa, 70 years old, has regained her confidence after suffering from years of disability and discrimination. Due to the stigma and ignorance surrounding leprosy, she was thrown out of her community in eastern Niger. She once had to beg for food but now she is earning a living and can feed and clothe herself.

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We conduct innovative research in collaboration with universities, research groups, governments and Ministries of Health worldwide. Our thanks go to all our research partners including:

- All India Institute for Medical Sciences, India
- Armauer Hansen Research Institute, Ethiopia
- Ashiyyan Medical College, Bangladesh
- Bombay Leprosy Project, India
- Colorado State University, USA
- Erasmus MC, the Netherlands
- Foundation for Medical Research, India
- Global Leprosy Programme, WHO SE Asia, India
- Griffith University, Australia
- Indian Council of Medical Research, India
- Indian Institute of Public Health, India
- Institute of Himalayan Bioresource Technology, Palampur, India
- Instituto Lauro de Souza Lima, Brazil
- JALMA Institute, India
- Khulna University, Bangladesh
- Leiden University Medical Center, the Netherlands
- Leonard Wood Memorial Center, Philippines
- Lepra Blue Peter Public Health & Research Centre, India
- London School of Hygiene & Tropical Medicine, UK
- National Hansen’s Disease Programs, USA
- National Institute for Mental Health and Neurosciences, India
- Oswaldo Cruz Institute, Brazil
- Post Graduate Institute for Medical Education and Research, Chandigarh and Delhi, India
- Royal Tropical Institute, the Netherlands
- Schieffelin Institute of Health, India
- The Maharaja Sayajirao University, India
- University College of Medical Sciences, Delhi, India
- University of Jos, Nigeria
- University of Kelaniya, Sri Lanka
- University of Leeds, UK
- University of Warwick, UK
- Vardhman Mahavir Medical College, India

We acknowledge that there are gaps in our toolkit including an urgent need to develop an early diagnostic test; a game changer in our quest to end leprosy.

We also need new tools to manage leprosy complications and improve the treatment of leprosy reaction. If we are to prevent disability and enhance the quality of life of those affected, we need tools to strengthen their physical, social and inner wellbeing.

We cannot develop all the tools that we need to achieve our vision. Our highly prized partnerships enable us to develop the evidence-base and obtain the funding we require to defeat leprosy and transform lives.

For general research information please check our website: www.leprosymission.org/our-work/research

For enquiries about research in India please contact: joydeepa.darlong@leprosymission.in

For enquiries about research in other countries or general research enquiries please contact: deanna.hagge@leprosymission.org

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Left: Women affected by leprosy at Nilphamari Hospital, northern Bangladesh.
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Front cover photograph: Diagnosing, treating and raising awareness of leprosy, Kushtia, Bangladesh.
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