UNFINISHED BUSINESS

Stopping transmission
- Better understanding transmission
- Early diagnostic tests
- Prevention of transmission
- Epidemiology and mapping
- Improving service provision
- Effective awareness strategies
- Innovative approaches to leprosy control

Preventing disability
- Clinical management of leprosy complications
- Economic effects of leprosy-related disability
- Improving early diagnosis
- Effective CBR programmes
- Cross NTD and disability studies
- Innovative approach to prosthetics and orthotics

Promoting inclusion
- Stigma and discrimination – its measure and interventions
- Effective approaches to support the mobilisation and empowerment of leprosy people’s organisations
- Leprosy and human rights
- Inclusive employment
- Inner wellbeing (mental health)
Who we are

The Leprosy Mission (TLM) is a Global Fellowship of 32 member countries. We are active in more than 40 countries around the world. We work hand-in-hand with governments and local communities, UN bodies, local non-governmental organisations, local churches, and many others to achieve our vision of: ‘Leprosy defeated, lives transformed’

Why research with TLM?

- TLM 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.

More recently, we have been involved in studies investigating the effectiveness of community-based rehabilitation as well as increasing our social studies research portfolio looking at topics such as stigma and discrimination, empowerment and life-course research.

We have experience in both quantitative and qualitative research and where we lack the capacity ourselves, our partnerships with other researchers allow us to tap into their capacity.

- TLM owns internationally recognised laboratories in India and Nepal.

The Stanley Browne Research Laboratory (SBL) in New Delhi, India, has a significant publication record for molecular and drug resistance studies including leprosy viability investigations (nasal and environment sampling).

The Mycobacterial Research Laboratory (MRL) at Anandaban Hospital in Kathmandu, Nepal, has a history of clinical, molecular and immunological international collaborative partnerships, currently including: Leiden University Medical Centre (The Netherlands); London School of Hygiene and Tropical Medicine (UK); and the Department of Health and Human Services National Hansen’s Disease Programs (USA).

Both SBL and MRL participate as sentinel sites nationally and within the World Health Organisation (WHO) Global Surveillance Programme for Leprosy Drug Resistance.

- Cutting edge biomedical research is conducted in collaboration with universities and research groups in Asia, America, Australia and Europe, focused mainly on transmission, diagnosis, leprosy reactions and drug resistance monitoring.

- TLM has a strong field presence as a direct programme implementer, employing around 2,000 staff.

Our programmes include referral hospitals, leprosy control initiatives and community-based health and rehabilitation projects. Together they provide a platform for clinical, social, epidemiological and operational research.

Our clinical work in endemic countries keeps us in daily contact with people affected by leprosy.

- We are involved in international, multi-disciplinary networks which enable us to further the research agenda and to bring the results of research to practical application.

This involvement is growing and is a strategic priority to increase our impact.

- Current global research collaboration is taking place in Bangladesh, DR Congo, Ethiopia, India, Mozambique, Myanmar, Nepal and Nigeria.

Where we work

[Map of countries where TLM is active]
The following pages outline some current research projects we are involved in ...
Promoting inclusion

Civil Society Organisations, Resource mobilisation, Empowerment, Advocacy, Training and Employment of people affected by leprosy (Create) in India – Research into stigma and discrimination


CREATE project will be working across four Indian Districts from 2016 – 2018. A core component of the project is operational research – related stigma and the effectiveness of measures to combat this stigma and promote inclusive development for people affected by leprosy and disabilities. Field research is being conducted by the project team who are also training people affected by leprosy to gather their own data in order to provide an evidence-base for their advocacy efforts.

Mixed method data collection will be used by the researcher to analyse stigma and discrimination reported through data sources. This will eventually lead to the development of a stigma toolkit, which will help civil society organisations representing people affected by leprosy and disabilities to identify stigma and develop effective approaches to combating it.

The objective for this piece of research is to assess improvements in social acceptance and dignity of people disabled by leprosy after adult literacy in four districts of North West Bangladesh. There are about 4,000 disabled people living in these districts who have completed anti-leprosy treatment under The Leprosy Mission International-Bangladesh and are followed up annually. Seven hundred Self-Help Groups (SHG) have been formed as part of a Community Based Rehabilitation (CBR) Project amongst people disabled by leprosy.

To facilitate participation in SHGs, 30 adult literacy classes were established and participants completed a 10-month course. Of the 300 participants in the literacy classes, 10 were selected for an interview to enquire more about their social acceptance and dignity. The subjects were asked questions on the following areas of their life:

1. Experience of leprosy disability and destitution.
2. Social relationships, acceptance and support by family and community.
3. Economic development and mental satisfaction

Almost all 10 interviewees spoke of their life history being affected by leprosy and disability, family and society. Because of leprosy they lost their limbs, dignity and quality of life. After being involved in a SHG their life experiences were improved.

They participated in adult literacy classes for 10 months. After completion of the literacy course they were able to read the Bengali newspaper, posters, signboards, and leaflets as well as write minutes of group meetings and maintain all other registers. In addition, they were able to monitor their personal income and expenditure, write letters, and use a mobile phone. Some of them have become leaders of SHGs and support other SHG groups.

Participants report that the community where they live now respects them and in some cases they are taking on the role of community advisor.

Increased social acceptance and dignity of leprosy disabled people after adult literacy

Lead Researcher: Dalwor Hossain. Co-researcher: Bob Bowers

Partnered with: Menzies Health Institute Queensland, Griffith University, Australia; The Leprosy Mission International Bangladesh, Danish Mission Council; The Leprosy Mission Denmark

Case study

Angels in blue work to defeat leprosy

Numkala Nuwani

Research is important but can only have an impact if its results are used to improve programme implementation.

Findings from The Leprosy Mission’s study in Bangladesh have shown that Rifampicin can be used as a post-exposure prophylaxis (PEP), helping to prevent leprosy in the contacts of index cases. This is now being rolled out in numerous countries, including Nepal.

Numkala Nuwani is one of 12 angels in blue, all Female Health Volunteers in a village in Kapilvastu district who are involved in both diagnosing and preventing leprosy.

Married with three children, Numkala has been a volunteer for 23 years and has encouraged many others to join the team. Educated at school up to grade 10, she understands the importance of health care.

She became a health volunteer because she wanted to help women in the community. Many women were not allowed to leave the home, and their husbands prevented any access to health clinics.

By becoming a health volunteer, she has been able to educate women about many health issues and support them and their children to access treatment. Training from The Leprosy Mission has enabled her and her fellow volunteers to identify the signs and symptoms of leprosy and ensure people access treatment.

More recently, the volunteers not only identified new cases but are now also involved in ensuring their contacts receive the single tablet that can help prevent the disease.

Numkala says: “As a volunteer we regularly undertake house-to-house visits, informing people about the disease and screening people.

“If it turns out to be leprosy, we screen all the people who have been in close contact, be it relatives, friends and work colleagues or, in the case of children, their classmates.

“Through the programme all contacts of every new person diagnosed will be given a single dose of Rifampicin to help stop leprosy.”
Our research partners include ...