

Our Annual Impact Review 2017-18

Leprosy is curable!

But left untreated, this cruel disease causes permanent nerve damage to people's hands, feet and eyes, leading to paralysis, blindness, ulcers and amputations.

The resulting disabilities from delayed treatment may not be possible to repair, causing life-long difficulties.

The cure, a course of multi-drug therapy (MDT), is simple and free - yet lack of knowledge and discrimination means many people struggle to access the treatment and support that they desperately need.

We work in India, Bangladesh and Mozambique to find, diagnose, treat and rehabilitate those affected by leprosy.



Bangladesh

Nilmoni's mother was worried that treatment for a skin patch that had lost sensation was not working and brought her daughter to one of our referral centres. We referred Nilmoni for Multi Drug Therapy (MDT) early enough to cure her before disability occurred, helping her to stay in school and work towards her dream of becoming a teacher.

Mozambique

When Joaquina was diagnosed with leprosy, she was in shock. She had not recognised the symptoms and postponed seeking treatment. Even though it was too late to prevent severe disabilities in her hands and feet, she was cured of the disease and was able to remain with her family. She is a regular visitor to our self-help group, learning self-care and helping to support others.



“Although my health will never get back to what it was, I'm happy. The members of the self-care group are like a second family to me. I can discuss my problems with them and we help each other.”

Joaquina



India

Aya visited a doctor after developing many skin patches that had lost sensation. He was wrongly told he could die within a year and that the cost of treatment was significant. After nearly a year, Aya was finally diagnosed with leprosy at a government health centre. During this time he had lost his job. Aya attended our Blue Peter Public Health and Research Centre where he was cured free of charge and was able to return to work and is telling others about the centre and how they helped him.

Message from our Chair of Trustees and Chief Executive

The second year of our five year strategy has seen unprecedented challenges facing the charitable sector as a whole in the areas of safeguarding and new laws regarding personal data; challenges which Lepra has risen to meet. Changes to data protection laws (GDPR) remained an important focus to ensure the work we undertake continues to be compliant, ethical and transparent, whilst also ensuring that safeguarding and the wellbeing of our beneficiaries, donors, staff and volunteers is at the heart of what we do.

We remain increasingly concerned that leprosy is increasing in prevalence, especially in India. There are a number of reasons for this, not least the failure of institutions to maintain vigilance and a level of awareness since the World Health Organisation asserted that leprosy had been "eliminated as a public health problem in 2000".

For Lepra, re-building an awareness of the harm being done by leprosy and the urgency of the needs of affected people are high priorities. We are firm in our dedication to provide a holistic, people-centred approach and work in partnership with others to achieve these priorities.

Early case detection is a key part of Lepra's work, engaging with communities burdened by disease, diagnosing people in rural locations and referring them for treatment without cost. This approach has allowed us to find, diagnose and treat 18,500 people living with leprosy, 30% more than last year.

Our aim is that, as more people receive treatment and support within the community is made easier to access, prejudice towards people affected by leprosy will reduce. Looking ahead, a key focus for research and programme interventions in 2018-19 will be three mutually supportive strategic pillars:

- **Health System Strengthening (especially at local level)**
- **Community volunteer / civil society active case finding / referral**
- **Promotion and support of self-care and self-help groups of people affected by leprosy and Lymphatic Filariasis (LF)**

We will continue to challenge negative stereotypes around leprosy; how it is portrayed and how it is spoken about. Use of the word "leper" and referring to leprosy in situations where it doesn't belong prevents inclusion and can cause real distress to those affected by the disease.

The year was marked by Lepra's active engagement in a number of international fora including:

- **ILEP Neglected Tropical Disease (NTD) Mapping**
- **Disease Management Disability and Inclusion (DMDI) meetings**
- **The inaugural meeting of the Global Partnership for Zero Leprosy (GPZL)**

In a number of these international meetings, Lepra took a leadership position, particularly on the topics of mental health, NTD mapping and monitoring and evaluation indicators.

At the UK level, Lepra engages with the following groups and academic institutions:

- **Bond Disability and Development and Mental Health groups**
- **All Party Parliamentary Group (APPG) on Malaria and NTDs**
- **London School of Hygiene and Tropical Medicine (LSHTM)**
- **Liverpool School of Hygiene and Tropical Medicine (LSTM)**

A renewed global interest in leprosy and LF will offer Lepra the opportunity to capitalise on our specialist expertise supporting people affected by these two diseases. The challenge, as ever, will not be the definition and formulation of appropriate programme interventions, but rather mobilising the funds required for their implementation.

Working towards the day when leprosy becomes a disease of little consequence is not only possible, but achievable. We wish to thank you all for your support in helping to achieve this.

We will beat leprosy together!



Charles Bland, Chair of Trustees



Geoff Prescott, Chief Executive

The numbers



We reached **301,000** people through diagnosis, treatment and care.

301,000

We found, diagnosed and treated **18,500** people living with leprosy. That's an increase of **30%** compared with the previous year, thanks to enhanced active case finding and health awareness activities.



30,000



We issued **30,000** pairs of protective footwear, enabling people affected by leprosy and lymphatic filariasis (LF) to walk without fear of injury and lead a normal life.

436

people affected by leprosy received reconstructive surgery to restore the movement and appearance of their hands and feet to reduce stigma and rebuild self-esteem.



135,000

We trained **135,000** health workers, volunteers, community champions, school teachers and government health staff to help reduce medical misdiagnosis and ensure that people affected by leprosy are diagnosed in the early stages.



263,000

We helped **263,000** people receive the disability grants and services they are entitled to. This support helps to reduce poverty, where leprosy and other neglected diseases have prevented a person from earning a livelihood.

35,000

We trained **35,000** people affected by leprosy and LF on how to manage their own care, so they can prevent infections in the areas of their body damaged by disease and reduce any further disability.



1.7 million



We reached **1.7 million** people through health education and events to raise awareness of leprosy and other neglected diseases. This helps people to recognise their symptoms, seek diagnosis and get treatment and reduce prejudice.



155,000

Of the 1.7 million, **155,000** children were reached through health education within schools.

Our impact in the field

India

This year, our work in Bihar, Jharkhand, Odisha, Telangana, Andhra Pradesh, Madhya Pradesh and West Delhi has changed the lives of 186,600 people by providing diagnosis, treatment and care. In four of these states: Bihar, Odisha, Andhra Pradesh and Madhya Pradesh, we have introduced combined leprosy and lymphatic filariasis projects, leading the way as an internationally recognised leader in this approach.

Reducing stigma and disability

Our work within communities has continued to build up leprosy knowledge and awareness whilst reducing the prejudice which leaves people at risk of discrimination, isolation and abuse. We reached over 373,000 people in India through community campaigns, helping to ensure they can now spot symptoms and access treatment without fearing the consequences.

We have continued to provide self-care training and protective footwear to support those where disability has impacted their lives. In total, we have provided footwear, self-care kits and other disability aids to 44,600 people in India to help them reduce infections and injuries and improve their mobility.

Beyond our delivery of health care services, we have successfully empowered over 263,000 people to advocate for their basic rights and claim government benefits to which they are entitled.



Pictured: Our sandals can be customised to fit each individual and support their needs.



An update from Rachna

Rachna Chhabra was diagnosed with leprosy in 2010.

“After my own leprosy diagnosis, I began to lose hope. I was irregular in taking my treatment and I isolated myself from my family and friends. Then I came into contact with Lepra, where I was counselled and given another course of multi-drug therapy (MDT) to ensure I was cured of the disease. Lepra does such amazing work to integrate a society that has been ignored. I now work for Lepra, where my role is to ensure that people are aware of the support that is available to them. I really am very proud to be able to help other people like myself.”

Did you know..?

21% of all Lepra staff in India have been personally affected by leprosy or LF.



Bangladesh

This year we have reached 113,900 beneficiaries through diagnosis, treatment and care across the districts of Bogura, Natore, Sirajgonj, Pabna, Dinajpur, Lalmonirhat, Kurigram, Sylhet, Maulvibazar, Habiganj and Sunamganj.



Access for everybody

In Bangladesh one of our key priorities has been to provide screening and support to marginalised communities. These localities are often neglected from mainstream health services as they are located long distances from medical facilities.

Of the people we reached this year, 98% were from vulnerable and marginalised groups, and 10% of these were living in indigenous communities. In total, over half (54%) of the people we supported were living in extreme poverty, not earning enough each day to sustain a healthy level of nutrition. Our work within these communities is imperative to ensure that these most vulnerable people have access to the healthcare they desperately need.

Community Champions

We trained over 1,100 Community Champions in Bangladesh, 39% of these had been affected by leprosy themselves.

Our Community Champions raise awareness of leprosy within their communities, screen for potential cases and refer these for diagnosis. Throughout the year, our Community Champions found 18% of all leprosy cases we diagnosed in Bangladesh and met over 46,000 people through their awareness raising activities.

The gender gap

Women in Bangladesh, and many other developing countries, still face barriers which prevent them from seeking medical treatment for leprosy. These include cultural practices and beliefs which mean they must be accompanied by, or receive permission from, a male family member when visiting a doctor and they also cannot be examined by a male doctor.

Women often prioritise their families and household responsibilities over their own health. It is common for the initial symptoms of leprosy to be misinterpreted by women and their partners as a minor skin complaint which means treatment is only sought after disability occurs.

Our female Community Champions break down these barriers; they can visit women alone in their home, removing the need to travel long distances, and discreetly provide advice and diagnosis. This year, over 400 of our newly trained Community Champions were female, allowing us to access more women and provide early treatment to help avoid disability.

Pictured: A Community Champion examines a man in the Tea Garden district, checking for signs of leprosy.



Mozambique



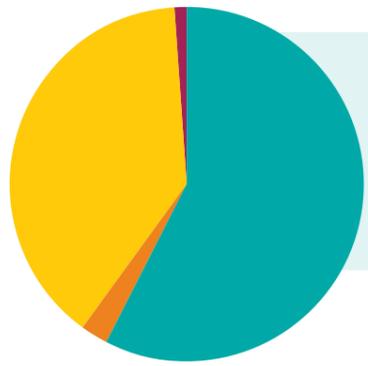
Alongside our partner, Netherlands Leprosy Relief (NLR), in 2017-18 we reached almost 500 people through diagnosis, treatment and care in the Zambezia Province. Over 7,200 people were taught about the symptoms of leprosy and other neglected diseases.

We also began a new project in partnership with NLR and the Adventist Development and Relief Agency which will run until 2020. This project aims to provide 5,000 people in affected communities with agricultural training to improve their nutrition and earn a livelihood. 300 of these beneficiaries will also be supported with treatment and care for leprosy and disability.



Image credit: Sajsa van Vechgel

Where your donation goes



Where our income came from

Total income	£5,272,189
Public support	£3,039,647
Trusts and business	£127,850
Statutory grants and charitable acts	£2,053,240
Sales, investments and other	£51,452

Did you know?

88p in every £1 directly funds our projects. The remaining 12p helps us to bring in the next £1.

How our income was spent

Total expenditure	£5,516,553
Charitable expenditure: projects, programmes, research, education, etc.	£4,828,716
Fundraising	£687,837

The financial information has been audited and presented to Lepra's Board of Trustees.

Our supporters

We have received over **£3 million** from individual donors in 2017-18. This amazing sum has enabled us to continue our work to find, treat and rehabilitate people affected by leprosy so they can transform their lives.

Our fantastic supporters have taken part in so many different fundraising activities to improve the lives of people affected by leprosy. A total of **£670,710** has been raised through community fundraising activities and events, with over **£500,000** coming from the support of school students!



The students from St Mary's Colchester raised **£3,545** with races, sweet sales and school sleepovers!

If you'd like Lepra to visit your group, school, university or organisation to demonstrate how your support can change lives, please get in touch!

In 2018-19, we need to raise £5.5m from our supporters, including major donors, corporates, groups and associations, trusts and foundations, schools, colleges and universities, fundraising events and challenges. This will ensure that we can continue to provide the support, care and assistance so desperately needed in India, Bangladesh and Mozambique.

Corporate partnerships

Pavers Shoes funds one of our mobile footwear vans that travels across Bihar to deliver custom-made sandals to people affected by leprosy and lymphatic filariasis (LF). The sandals, which are designed, made and fitted by our specialist footwear technicians, help people to go about their daily lives without the threat of injury, infection or being identified via their footwear as being affected by these diseases. In 2017-18, the van travelled over 4,300 miles and provided protective footwear for over 2,500 people.



Haddenham Healthcare, West Suffolk NHS Foundation Trust and Ipswich Hospital NHS Trust provided compression garments to help alleviate swelling caused by LF. These garments were given to 215 beneficiaries in India, helping to improve their mobility.

Empowering communities to tackle leprosy and lymphatic filariasis

Our SANKALP project in India (meaning determination or solemn vow) has worked since 2015 to build both capacity within eight government centres and to empower communities to tackle leprosy and LF in a sustainable way.

This pioneering project has run in six blocks in Odisha, opening Morbidity Management and Disability Prevention (MMDP) clinics at the government health centres, which break down major barriers to seeking treatment alongside other patients without fear. SANKALP also empowers people to take ownership of their treatment through forming community groups where they can find information, receive support and self-care training and pass the training on to others.

Education and awareness raising is equally a focus; we have trained 2,838 students and 223 teachers about leprosy and LF, along with ways to prevent infection by using mosquito nets and hygiene. We have also trained 18 local footwear technicians to make safe, comfortable footwear within the community, providing a valuable resource for those who are disabled by these diseases.

By educating people and changing attitudes, the number of people reporting they have experienced stigma has been reduced by 37%. With more protective footwear being available, mobility and employment opportunities will also improve for people affected and their families.



"If you did not do this for me I could not be well."
Shumi, Bangladesh



Strengthening health services and information in Bangladesh

Community Level Health Systems Strengthening (CHLSS) is a 3 year project that works to improve early detection and integrate leprosy care in 8 districts in Bangladesh. The project has trained medical professionals, Community Health Care Providers and Community Champions to recognise and refer cases of leprosy early. Since the project began in April 2016, the number of people diagnosed with existing disabilities has more than halved, from 11% to 5%.

The project has also helped people where diagnosis came too late to prevent disability; Shumi was found by one of our Community Champions; she had been living away from her family and had spent 10 years walking on her knees due to her disabilities. We referred her to the government health centre where Shumi was not only treated successfully but was also given a wheelchair to help her regain her independence. She now lives with her family again and is happy to be well.

As we approach the end of the third year in March 2019, the project has been hailed a success, having trained 2,700 people, including medical professionals and Community Champions to recognise and understand leprosy symptoms. They have screened over 86,000 people, with 1,500 of those people being urgently referred for further tests or treatment. People like Shumi, would not have been found without the project and your support.

We would like to thank everyone who has contributed to our work this year whether you have given your time, money or support to Lepra. We will beat leprosy together.



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Corporate partners

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We would like to thank all the donors, organizations, trusts and foundations who have assisted us to transform lives and raise awareness, including:

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UK Aid Direct
UNICEF
University of Texas
Vivekananda Mission Ashram
Vodafone Foundation
The Westwood Charitable Trust
The White Family Charitable Trust
World Vision
The Wyndham Charitable Trust

Additional Thanks

Navaz Batliwalla
Jo Brand
Jamie Chadwick
Foyzl Choudry
Joseph Fiennes
The Rt Hon. The Lord Fowler
Stephen Fry
The Lord Gadhia
Hindu Council UK
Claire King
R. Madhavan
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