HELPING TO HEAL
THE BODIES AND LIVES OF THOSE AFFECTED BY LEPROSY
How we help
Leprosy remains one of the world’s most stigmatising diseases, commonly resulting in individuals affected by the disease being isolated from their education, career and marriage prospects. They are often shunned by their family and friends and pushed to the fringes of society, leading many to beg as their only hope of survival.

The combination of a disease that has a severely debilitating effect on the body and the stigma surrounding it means a unique and effective approach is required to care for a person’s needs. Our work is broad and far-reaching. We tend to the physical, social, spiritual and psychosocial needs of a leprosy-affected person. One of our most successful projects has been to prove the case to be made for spending on those in need by the international community.

Causes
Most people are naturally immune to the Mycobacterium leprae bacillus that causes leprosy. People living in poor communities, too often thousands of people globally who have re-built their lives after having them torn apart by leprosy.

Infectiousness
Once infected with leprosy, the bacillus can lie dormant for many years, only to reactivate when the body’s defences are weakened by, for example, poor nutrition and deficiency of vitamin B12. However, this disease is not contagious: there is no lasting damage. Leprosy starts when the bacillus enters the skin’s surface resulting in a loss of function of the peripheral nerve system. Consequently, the skin feels numb and pain, everyday activities are fraught with danger. Unnoticed burns and ulcers can lead to permanent disability. For example, a lack of feeling in the eye, blindness is a common consequence of leprosy.

New cases
Published in August 2012 by the World Health Organization, there were 213,075 new cases of leprosy diagnosed in 2011. This is approximately one every two minutes. More than half of these were found in India. Due to the stigma associated with the disease, however, and the underreporting due to fear of discrimination in many of those affected, the number of new cases is underreported.

Where we help
The Leprosy Mission’s global family currently works in 26 leprosy-endemic countries. The Leprosy Mission England and Wales focuses on 11 countries in Asia and Africa. The needs of individuals and communities vary significantly between the nations in which we work.

The Mission currently works in these Asian and African countries to provide care and a range of different projects that help transform the lives of leprosy-affected people as well as working to eradicate the social stigma and consequences of the disease. There are no longer any who have not been treated as a result of the late treatment of leprosy.

Like many charities, The Leprosy Mission England and Wales has been impacted by a difficult financial climate both at home and overseas.

Following a steady decline in our income during recent years, I am delighted to report the trend was reversed in 2012 with our income rising by 13 per cent to more than £6 million. This was achieved during a period of restructuring at The Leprosy Mission England and Wales. We take very seriously our responsibility to be the very best stewards of the money given to us in good faith by our supporters.

We must keep our administration costs to a minimum in order to maximise our overseas support for people affected by leprosy. The majority of the end of year surplus was allocated to overseas projects in early 2013.

As we continue to focus our efforts on transforming the lives of individuals and communities in 11 countries across Asia and Africa, I thank you for your continued support and interest in the life-changing work of The Leprosy Mission England and Wales.

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Welcome
2012 was a pivotal year for The Leprosy Mission England and Wales with us having to make some tough decisions about expenditure and investment in fundraising. We are now on track to help an increasing number of people affected by leprosy – some of the world’s poorest and most marginalised people.

Through the generosity of our loyal supporters and hard work of our committed staff, I am confident that we are set to meet our target of committing increased funds to overseas projects year on year.
We are passionate and proactive in our work, maximising opportunities for early diagnosis and treatment so that leprosy patients are left with no lasting disability. This can be through an outpatients’ department at a local hospital or by innovative outreach projects, such as our Karuna ambulance project in Mumbai, India (see page 13).

Tragically, even after treatment, the disease may have developed significantly and caused permanent damage to a patient’s nerves. The good news is a ‘clawed’ hand or ‘drop foot’ – caused by muscle paralysis – can be restored with surgery allowing movement once again. Likewise the eye’s ‘blink’ mechanism can be restored by surgery, sparing a person from going blind. We enable thousands of people affected by leprosy to undergo reconstructive surgery each year, allowing them freedom from severe disability, restored eyesight and a much-improved quality of life.

Self-care is key
We coach people within leprosy-affected communities to lead self-care groups to help minimise the risk of injury caused by nerve damage. Group members examine each other for injury and encourage one another to seek treatment for their wounds. In some cases, the late treatment of leprosy can cause a person’s feet to become so infected that they can no longer walk on them. Although it may take months of hospital rehabilitation, we will always seek ways to help patients become more mobile and prevent a desperate situation of a limb having to be amputated. Due to the stigma still surrounding leprosy, a person’s emotional wounds can be as great, or even greater, than their physical needs. Counselling and tending to the spiritual needs of people affected by leprosy are an integral part of our care and health services.

Case study
Manju Ray first showed signs of leprosy soon after her marriage, aged 14. There is deep stigma surrounding leprosy in Kolkata, India, and Manju did not seek treatment for the disease when she first noticed light patches on her skin. Manju’s health had become so bad that she could no longer walk on her feet. Her husband told her to leave home. Her right leg had to be amputated following terrible ulcers and her remaining leg became infected. She suffered nerve damage in both hands. Leprosy caused the muscles in Manju’s face to weaken and for more than 10 years she was unable to close her eyes. Leprosy caused the muscles in Manju’s face to weaken and for more than 10 years she was unable to close her eyes. Manju's fears became real as on discovering she had leprosy, her husband told her to leave home. Her right leg had to be amputated following terrible ulcers and her remaining leg became infected. She suffered nerve damage in both hands. Leprosy caused the muscles in Manju’s face to weaken and for more than 10 years she was unable to close her eyes. Leprosy caused the muscles in Manju’s face to weaken and for more than 10 years she was unable to close her eyes. Despite her eyes becoming injured, Manju did not go blind. She arrived at The Leprosy Mission’s Premananda Hospital in Kolkata complaining of blurred vision. She was given eye surgery in both eyes. Manju will never have perfect vision, but the operation has saved her remaining sight.
Children affected by leprosy are usually from the poorest of poor families. A barrier to education may be something we would consider a small hurdle, such as not being able to buy or borrow a school uniform or a pencil case. But it can be stigma. Surrounding leprosy often see a child from a leprosy-affected background as a social outcast. Many schools will refuse to admit children unless they can prove they do not have leprosy. Stigma is not just a problem of the past. It’s still present today.

Case study

Tanimoune Tsalha, 16, lives on the Danja Hospital site in Niger where we fund care for leprosy patients. Six years ago he was diagnosed with leprosy by a missionary health worker visiting his home village 100km away from Danja. He had red patches on his arms for a year prior to this but ignored them.

Leprosy caused Tanimoune to find it increasingly hard to blink and friends at his previous school began to laugh at him. For that reason he decided to stay in Danja after receiving treatment. He still has a problem with his right eye but is doing exercises in an attempt to strengthen the blink mechanism.

He said: “My friends started rejecting me and I was unhappy. When I came to the hospital I had an ulcer on my left foot.* If I did not come to Danja maybe I would have lost my fingers, toes and my friends.”

*if left untreated, this could have resulted in septicaemia.

Give a child a bright future today. £30 provides a school uniform and the equipment required by a child to start school. Visit leprosymission.org.uk/donate/give-a-gift-for-life.aspx

Every year we enable thousands of children from leprosy-affected families to go to school. One of the schemes we fund is a child education project called Iphiro Yohoolo in Cabo Delgado, Mozambique. Its purpose is to get leprosy-affected children, orphans and youngsters with disabilities into school and encourage them to achieve their full potential.

Most people in Cabo Delgado are subsistence farmers, often living in terrible poverty. A good quality education is a way to break the cycle and help future generations to succeed.

There are huge obstacles to a young person affected by leprosy succeeding in life. This can be a result of stigma or a leprosy-caused disability excluding them from employment. Tragically, this leaves many begging as their only hope of survival. Each year, however, The Leprosy Mission helps thousands of young people affected by leprosy and disability train to do a skilled job. As well as seeing them able to fend for themselves and boosting their confidence, many go on to support their entire family and have families of their own.

Transformation through job training

The Leprosy Mission runs six vocational training centres in India that are connected to local businesses for work placements. Aspirations among young people affected by leprosy are usually low with most being more than happy to take a job as a road sweeper. At the vocational training centres students are taught skills including motor mechanics, radio and television repairs, computing, tailoring, handicrafts and small business management so that they are highly employable or have the training required to set up their own small businesses.
Leprosy is one of the world’s most stigmatised diseases. In India, entire families have been affected by the disease, education and marriage prospects destroyed as a result of age-old stigma and misunderstandings surrounding the disease. A myth still prevalent in the world today, is that leprosy is a curse for something you have done wrong, an untruth we work hard to counter. Advocacy is a key element to our efforts to tackle the disease and its consequences. We have had some significant successes in our advocacy efforts for people affected by leprosy in 2012.

Help us eliminate leprosy and its devastating consequences by signing up to our Leprosy Out Loud! charter. Visit leprosymission.org.uk/join-with-us/young-people/leprosy-out-loud.aspx You can also ‘like’ us on Facebook by searching for Leprosy Out Loud! or follow us on Twitter @H_R_Defender

In the UK

The Leprosy Mission was integral in the successful advocacy efforts that saw Aardman Animations drop a controversial scene from the 2012 Oscar-nominated animation The Pirates! In an Adventure with Scientists. The scene originally depicted a character on board what was termed a ‘leper ship’, showing his arm falling off for comic effect.

In March we welcomed Prime Minister David Cameron’s acknowledgement that disability is a serious issue that must be prioritised in the Post-2015 Development Goals. Disability was not mentioned in the original Millennium Development Goals despite 650 million people worldwide living with a disability. This followed our submission of written evidence to the International Development Select Committee, which was referenced in its report published in January 2013. We stated there was a high incidence of disability in developing countries and that priority should be given to the prevention of disabilities and rights given for people with disabilities.

Case study

Gugadhha is the only person living in Ashodhar village in Uttar Pradesh, India, who is affected by leprosy. Now widowed, Gugadhha does not know her age but moved to Ashodhar when she married. It was at this time she began developing disabilities and was eventually diagnosed and treated for leprosy.

Gugadhha was previously forbidden by villagers to take water from the common well because of her state of leprosy. A worker for our Challenging Anti-Leprosy Legislation (CALL) project challenged villagers on this. They now help Gugadhha at the well, a kindness greatly appreciated as she struggles as a result of the leprosy-caused disabilities to her hands. Interestingly, the villagers have also permitted her to take water from their wells, but with Gugadhha’s two sons and their wives. Since her sons married they live in two neighbouring homes and Gugadhha lives in a makeshift shelter between the two houses. She says she is not allowed to live in either home because she is leprosy-affected. This is despite giving her pension.

One of her daughter-in-laws said: “She is an infected person and I’m not.”

We continue to address the misconceptions.
The Leprosy Mission’s aim is to empower people affected by leprosy, providing them with a springboard to living healthy and fulfilled lives. A true transformation cannot take place if a person has to beg in order to eat and remains living in poor living conditions. A basic home and a job are the foundations on which to build a future of self-sufficiency.

As well as providing professional job training, we nurture self-sufficiency by providing business loans to people affected by leprosy so that they have the means to establish a small enterprise. As a result of a grant from the European Commission, we are part-funding a livelihood project in Bangladesh to benefit households headed up by women, in particular people with disability and affected by leprosy.

A home of their own
Many people affected by leprosy live in basic shelters with inadequate sanitation because of poverty, exclusion or an inability to assert their rights. Often they lived as part of a leprosy-affected community that has been evicted from the land they called home.

This was the case for a community living in Niger’s capital city Niamey at the beginning of 2012. They were forced to live in makeshift shelters and were frequently moved on from wherever they set up camp. We managed to secure some land on the outskirts of the city and built a community of 22 homes. As every person has been affected by leprosy there’s a spirit of unity and understanding. There’s even a water borehole providing clean, safe drinking water and a source of income.

Case study
Louisa lives in the village of Obaju in the Cabo Delgado province of Mozambique. She is her brother’s carer after he went blind as a result of leprosy. Louisa takes care of her brother as well as her own family. She gives him a home and cares for him. The Leprosy Mission helps fund the Leprosy Association of Mozambique (ALMEmo) groups that offer support to people affected by leprosy and help raise their voice in the community.

Louisa is skilled at making pottery by hand – a talent her ALMEmo group has nurtured so that she can earn a living and support her brother as well as her own family. The group has encouraged her to start her own pottery business and she is now, due to demand, able to expand and take on her daughter as an apprentice.

Buy a leprosy-affected community a home today; £900 will buy a new house. Visit leprosymission.org.uk/donate/give-a-gift-for-life.aspx

HIGHLIGHTS
• 910 leprosy-affected households headed up by women received help to earn a living in Bangladesh in 2012. Bangladesh is a male-dominated society and women with leprosy are particularly vulnerable as they face severe stigma and exclusion.
• 40,000 patients using Danja Hospital in Niger and the poor communities surrounding the site benefited from a fresh water supply in 2012 after we constructed a water tower.
• We are working with the Ethiopian government to provide 120 toilets, 72 shower rooms, clean drinking water points and implement a drainage system to benefit those living in the Woreda 1 slum in Addis Ababa.

livelihoods, housing & sanitation
40,000 patients using Danja Hospital and those living in the surrounding communities have access to a clean water supply following the construction of a water tower. Residents of nearby Danja village previously had to walk 2km to collect water from a well – a task that proved difficult for people with leprosy-affected hands and feet.

2 Nigeria
The Chanchaga Orthopaedic Workshop in Minna is situated next to the Chanchaga leprosy colony. It produces bespoke orthopaedic devices for hundreds of leprosy-afflicted people each year. The prostheses, walking aids and protective footwear greatly improve a recipient’s mobility and quality of life.

3 Sudan
The Aburoff clinic in Khartoum is Sudan’s only specialist leprosy centre. People affected by leprosy travel across Sudan for treatment and use its services. The clinic provides medical help with self-care in a bid to reduce the number of injuries leprosy-affected people sustain as well as acting as a training centre for government staff.

4 South Sudan
We are working with the government to plan health services as well as housing, water and sanitation projects to benefit two leprosy communities on the outskirts of Juba.

5 Ethiopia
We are working with the Ethiopian government to provide 120 new toilets, construct 72 shower rooms, create 12 clean drinking water points and implement a drainage system to improve sanitation in the Woreda 1 slum in Addis Ababa. This will improve the quality of life and general health of thousands of leprosy-affected people.

6 Mozambique
Our brothers Yiholico school project saw uniforms and equipment given to 275 children in 2012, enabling them to go to school. These are children who are either affected by leprosy or disability in the poor Cabo Delgado province. The children are learning social skills and being taught how to help them gain employment and break the cycle of poverty.

7 India
More than 1,500 leprosy patients were treated at the Karuna mobile clinic in 2012. The project uses a converted ambulance with doctors and nurses on board to treat leprosy communities and slums in Mumbai, diagnosing leprosy and providing medical care to both those affected by the disease and other medical conditions they are too poor to have treated elsewhere.

8 Nepal
Anandaban Hospital is situated 20 miles south of Kathmandu and acts as a magnet for those seeking treatment. Its staff treated and cared for 5,316 leprosy-affected outpatients in 2012. A total of 137 new cases of leprosy were diagnosed at the hospital during this time.

9 Bangladesh
127 patients attended mobile clinics in the slums of north Dhaka where they were tested for leprosy and other conditions. The urban slum improvement programme also provides unique opportunities for leprosy-affected people to earn a living.

10 Myanmar (Burma)
667 people affected by leprosy were cared for at 15 disability resource centres across Myanmar in 2012. In December a specialist clinic on-board a truck was launched. It tours the 15 disability resource centres making and fitting prosthetic limbs for leprosy patients.

11 Sri Lanka
Regular medical camps and health clinics were held in poor communities in the Jaffna district. A total of 1,018 people received treatment for a variety of conditions in 2012, the majority leprosy-related. As a result of a leprosy screening programme, 31 people received early diagnosis of the disease during the course of the year.
In July we believed we had no option but to launch an emergency appeal to help victims of the West African food crisis. Erratic rainfall resulted in a poor harvest in 2011. Subsequently food prices were sky high in the communities where we work in Niger, resulting in many going hungry. Leprosy-affected people tend to be the first to suffer in a famine as their incomes are often extremely limited as a result of their disabilities.

Staff members witnessed leprosy-affected parents travelling to the Ivory Coast and Benin – areas deemed more prosperous than Niger – to beg in a bid to feed their children who were left on the brink of acute malnutrition. Thankfully we had an overwhelmingly positive response from our generous supporters. In fact it was the largest response we have received to an appeal to date. Staff in Niger were able to buy up bags of millet, the staple diet, to distribute among five leprosy-affected communities. More than 4,000 people were helped and grain was put in storage to help those at risk of hunger in 2013. We were also able to plant trees in Danja village to protect the land from desert encroachment and aid future harvests. More than 4,000 people were helped and grain was put in storage to help those at risk of hunger in 2013. We were also able to plant trees in Danja village to protect the land from desert encroachment and aid future harvests.

In November that the UK is to end financial aid to India by 2015 due to the country’s rise as a global economic power. But while there is a burgeoning middle class in India, the country remains home to a third of the world’s poor. Around 500 million people live in slums on less than £1 a day. More than half of new leprosy cases globally – more than 100,000 a year – are diagnosed in India. Stigma surrounding leprosy is rife in India with many people affected by leprosy pushed to the fringes of society, unaware of their human rights and any benefits they might be able to claim from the government.

We have appointed two young ambassadors who have travelled to India to visit our projects. They are raising awareness among their peers in a bid to drive a global awareness of the human rights breaches people affected by leprosy face on a daily basis. The ambassadors will play an integral role in our emerging youth strategy which seeks to inspire a new generation to help transform the lives of leprosy-affected people.

Acknowledgements

Trust and foundations partnerships continue to make a crucial contribution to The Leprosy Mission England and Wales’s work. In 2012 our projects benefited from the generosity of, among others, the Vitol Charitable Foundation, James Tudor Foundation, Hand in Hand Charitable Trust, RCare (Midlands) Ltd and The Military & Hospitaller Order of Saint Lazarus of Jerusalem.
New beginnings

Thanks to the generosity of our supporters, The Leprosy Mission England and Wales has been able to provide a springboard for a new beginning to thousands each year. Through The Leprosy Mission’s overseas offices and partner agencies, we are alerted to leprosy-affected communities in dire need and continue to establish new projects to benefit the people living there.

Our latest challenge lies in South Sudan – the UN’s newest member state having been granted independence in 2011. It is a new country in need of renewed hope with one in seven children dying before their fifth birthday as a direct result of poverty. A leprosy-affected community is living in tents on the outskirts of the capital city Juba having been displaced from their land. They had very little to begin with but are now left destitute with their only goal being survival. Their healthcare is woefully inadequate and access to education non-existent. We are working with the government of South Sudan to set up a programme to diagnose and treat leprosy before it leaves a person disabled or robs them of their eyesight. We are working to improve this community’s living conditions and send the children to school.

Case study

This is Wara. He lives with his grandmother, mother and sister in the leprosy community on the edge of Juba. Angelica, his grandmother, can no longer work because of leprosy-caused disabilities and his mother, Nainara, struggles to earn enough to feed the family. Education, 10-year-old Wara’s only hope of breaking free from the chains of poverty, seems an impossible dream.

Making a difference

In 2012 our loyal supporters travelled to Asia and Africa to work on our projects and advocate on behalf of people affected by leprosy. Close to home, volunteers in their thousands took part in an array of fundraising events to support the work of The Leprosy Mission including running the London Marathon, zip wiring 950 feet across the River Tyne and trekking across the Brecon Beacons. Others hosted coffee mornings, asked for donations to The Leprosy Mission in lieu of presents for ‘significant’ birthdays and gave talks about our projects to friends and family.

For more details of the next Spinalonga trip, please email post@tlmew.org.uk or ring 01733 370505.

Spinalonga – where the memory of leprosy lives

Spinalonga island

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It costs just £20 to cure someone from leprosy.

Visit leprosymission.org.uk to find out more.

Visitors can walk among the faithfully-preserved remains of the leprosy-affected community.

The five-day trip incorporated a day trip to Spinalonga – dubbed ‘the island of outcasts’ – where visitors can walk among the faithfully-preserved remains of the leprosy-affected community.

The Samaria Gorge Challenge – which saw supporters hike 11 miles from the Omalos plateau in Southern Crete to the coast of the Libyan Sea, collectively raising thousands of pounds to help leprosy-affected people.

The Spinalonga trips came to the attention of Victoria Hislop who encouraged more supporters to witness first-hand the memories the island holds by joining the next trip. She said: “The Leprosy Mission is doing invaluable work to relieve the suffering of people affected by leprosy today and I wish all their supporters a happy and rewarding trip to Crete.”

Supporters take part in the Samaria Gorge trip.

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This summary financial information is not the statutory accounts but has been derived from the audited financial statements which were approved by the Trustees on Saturday 6 April 2013 and other financial information. The full statements have been audited and given an Unqualified report. Copies of the full statements have been submitted to the Charity Commission and the Registrar of Companies. This summary may not contain sufficient information to allow for a full understanding of the financial affairs of the charity. The full accounts, including the audit report, may be obtained from The Leprosy Mission England, Wales, the Channel Islands and the Isle of Man.

Finances 2012

IncomInG resources 2012

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Total incoming resources: £4,067,050

Gains/ (losses) on investment assets: £1,158,344

Costs of generating voluntary income: £1,533

Investment management costs: £1,533

Charitable activities: £48,507

Governance costs: £5,275,434

Total resources expended: £5,293,456

Net movements in funds: £856,221

Net incoming/ (outgoing) resources before other recognised gains and losses: £4,067,050

Statement of financial activities

Thank you for helping us provide essential services and support in 2012 for people affected by leprosy.