



Putting people first, we save and change lives

2011/12 in review



LEPRA
healthinaction

Patron: Her Majesty The Queen

People are more than mere statistics...



At LEPRAs, what we mean when we talk about impact is how we bring about lasting change in the health, social and economic status of individuals and their communities. This would not be possible without you.

On behalf of LEPRAs we would like to thank you for the impact you have made on the lives of real people through your support over the past year. You have saved and changed the lives of people living on the margins of society, for good.

If 2010 was a year of reflection for LEPRAs, then 2011 has been one of consolidation and moving forward with plans for the future. Over the past year we have continued our programmes in India and Bangladesh and strengthened our financial footing. In doing so we have met and exceeded the targets laid out in our 2010/11 review.

What this means is that LEPRAs is positioned with the firm financial foundations it needs to continue to save and change lives as we build towards our 90th year in 2014 and beyond. It is the support we receive towards our work, through donations, grants and gifts left in wills that has made this possible.

We are now moving forward from a position of strength and can continue to leave behind us a legacy of lasting impact for people; as ever we look forward to continuing that journey with you.

With sincere thanks for your most valued support,

Chairman

Chief executive

Cover image:

Savithri and daughter Vani have recently completed a gruelling treatment regime for Multi-Drug Resistant TB (MDR-TB).



Treatment for MDR-TB is 50-200 times more expensive than regular TB. Our TB work prevented more people developing or being infected with MDR-TB.



Behind the pills are people, like ten year old Venugopal who has a rat bite on his finger. Leprosy nerve damage meant he didn't feel it gnawing as he slept. MDT will cure leprosy; antibiotics will stop infection while steroids and physiotherapy will help him regain some function in his hands. For Venugopal this means that he can hold his pencil again at school.

Action through knowledge saves lives...

In 2011/12 LEPRAs reached more than a million people in India and Bangladesh with health messages on leprosy, TB and HIV as well as other health issues. We did this by going into communities and using a variety of engaging and entertaining methods to get our life-saving messages across.

The positive impact of this mass health education has been demonstrated in Bangladesh where 52 per cent of those who came forward for TB testing at LEPRA supported facilities did so after coming into contact with a LEPRA health education programme.

Leprosy and HIV awareness information aims to enable people to understand the causes, recognise symptoms and seek treatment early. It challenges preconceptions to dispel the myths and misconceptions associated with these diseases in an effort to reduce prejudice against those affected.

A public survey undertaken by our HIV/TB programme in Madhya Pradesh, India revealed that due to our activities some of the stigma surrounding HIV has now been reduced and 75 per cent of those asked would be happy to come forward for HIV testing, compared with 7 per cent at the start of the project.



Andhra Pradesh remains India's second highest HIV prevalent state. A six year project on empowering women in HIV prevention in Andhra Pradesh came to an end during the year. In this year, more than 90,000 women learned about HIV transmission and prevention, awareness of HIV services and condom usage from LEPRA. In total this project educated more than 400,000 women in HIV prevention.

LEPRA's health education vans and mobile TB/HIV testing units travel thousands of miles each year to save lives.

Between January and April 2012 we reached over 60,000 people in Bangladesh with health education and awareness information through school health and community talks alone.



"Initially I was embarrassed to talk about sex, now I can talk openly about HIV, AIDS and condoms in large groups of people I don't know."

Nori and Gierieja: Two young women helping others to understand and protect themselves from HIV.

The number of deaths of people with HIV using care and treatment facilities in Andhra Pradesh fell from 28 to just 2 per cent by the end of a four year USAID funded project: 'LEPRA SAMASTHA'. This was the result of building the skills and capacity of health staff, carried out through training and mentoring.

Turning lives around with care...



In 2011/12 you helped LEPROA reach over 700,000 people in India and Bangladesh with our services. Many of these people are pushed to the margins of society through poverty, disability, prejudice and cultural identity. The lack of access to health care and information they face puts their lives and livelihoods at risk. This makes your support all the more vital.

We were able to improve the lives of 165,000 people affected by leprosy and other poverty related diseases with specialist treatment and disability services that would otherwise not have been available. Together we enabled a further 164,000 people to obtain a diagnosis by providing testing and follow-up services.



One person starts treatment for leprosy every two minutes. As well as increasing leprosy detection within the general health care system through skills training and capacity development which make these large numbers possible, LEPROA staff directly found 2,250 new cases of leprosy in India and Bangladesh, and ensured that these people were treated. Reconstructive surgery was carried out on 306 adults and children disabled by leprosy to restore use of the hands, feet and eyes.

Services for leprosy diagnosis, treatment and disability care were provided through LEPROA's 24 referral centres in India. In Bangladesh LEPROA supported a further 24 health facilities to provide diagnosis and treatment in Rajshahi division, home to a quarter of the country's population and the country's highest leprosy case load. Across these two countries these centres continued to bridge the gap in leprosy service provision, for more than 20,000 leprosy affected people.

It can be difficult for disabled people to travel to access specialist disability services. LEPROA disability self-care camps continued to bring these services and training to almost 20,000 people affected by leprosy and lymphatic filariasis (LF) in areas where both diseases are endemic. This is a sustainable, cost-effective approach that enables those disabled by these diseases to undertake their own disability care at home. This increases their independence and reduces the need to travel long distances.

A survey of our LF project in Puri, Odisha revealed that after receiving self-care training 97 per cent of those trained continued to practice self-care regularly at home and 67 per cent had experienced improved mobility and reduced swelling, whilst 71 per cent had experienced no fever in the last 3 months.

We also facilitated 451 hydrocele surgeries*.

Dwija Rout: For Dwija, self-care taught by LEPROA means healthier skin free from infections. As a result he no longer loses weeks of his life to the debilitating fevers that accompany LF.

2,000 families are better-off thanks to socio-economic empowerment initiatives through LEPROA.



Exclusion to Inclusion self-help group meeting, Chirkuta village, Bogra: Our Exclusion to Inclusion project in Bangladesh has so far helped 144 leprosy affected people to generate an income.

***What is hydrocele?
A common side-effect of lymph damage caused by LF. Though not often mentioned, hydrocele is a collection of fluid in the scrotum causing enlargement. Left unchecked this will continue to swell. Hydrocele is a source of unhappiness, causing direct and indirect financial loss. Surgery to release fluid is simple and life can resume as normal afterwards.**

Placing help within reach...



LEPRA tested more than 56,000 people for HIV. We counselled those found HIV-positive, referring them for further HIV services and treatment with antiretroviral therapy.

We provided 48,000 people living with HIV and their families with counselling and regular follow up. Through this follow up and support we have reduced the death rate of HIV-positive people registered under our LEPRA SREYASSU project in Andhra Pradesh from 15 per cent to 4 per cent in the last year.

The transmission of HIV from an HIV-positive mother to her child during pregnancy, labour, delivery or breastfeeding is called mother-to-child transmission and occurs in around a third of cases. LEPRA's approach to reducing these rates of transmission involves counselling, referral of expectant mothers for HIV testing and promoting hospital births with prophylactic drugs to prevent HIV transmission. As a result, all of the babies born to the 50 HIV-positive mothers in one of LEPRA's prevention of mother-to-child transmission projects in Madhya Pradesh are HIV free.

TB is the leading cause of death in people with HIV. TB and HIV co-infection is a growing problem worldwide. This year LEPRA has cross-referred more than 10,000 people for TB/HIV co-infection testing. This resulted in the diagnosis of 660 cases and enabled life-saving, specialist treatment to be administered.

Some of the ways we increased TB cure rates in our areas of operation in both India and Bangladesh:

- **Testing more than 90,000 people for TB; one in 10 of these were found to be positive.**
- **Referring these cases for treatment, providing counselling and peer support to encourage adherence to the treatment regime through to completion.**
- **Training 400 village doctors in Bangladesh to properly administer TB drugs so that more patients adhered to the correct treatment until cured.**
- **LEPRA operated 300 TB sputum collection centres located in hard to reach areas across three states in India. This gives people in isolated communities the opportunity to be tested, treated for and cured of TB.**

One in 8 people affected by leprosy has eye problems. Cataracts are a leading cause of leprosy-related blindness. More than 35,000 people accessed services at the LEPRA Eye Hospital in Odisha and its outreach clinics, which continue to be financially supported by Sight Savers International. Here we carried out almost 5,000 cataract surgeries, and treated 18,000 people with minor eye complaints which could contribute to preventable blindness.

The average distance a sick or disabled person in Bihar must travel to the nearest clinic is 62 miles. Your support means that for some, help is closer to home.



Hydrocele surgery brought an end to Rakesh's humiliation. It meant that he could go back to school and play cricket again.

LEPRA's mobile HIV testing van provides HIV testing and TB referral.

In one project in Adilabad, India LEPRA increased the TB cure rate from 61 per cent to 92 per cent over the last year.



Kanduri's story: Stop TB in my lifetime

Kanduri Charan Nath is 76 and lives in Odisha, India. When he was ill with TB Kanduri couldn't even get out of bed on some days. Now he can easily cover 50 to 60 kilometres on his bicycle. Kanduri attends the regular TB meetings arranged by LEPRAs, held in the villages near his home. Here he shares his experience with other people.

"If nothing had been done by LEPRAs he told us, "I would have died."

The project that Kanduri is involved with, LEPRAs AXANYA, was set up to improve TB diagnosis and cure rates in Odisha, India.

Dr Jyotsna Mohapatra who heads up the project for LEPRAs says:

"It's 35km to the nearest TB testing centre, most people can't travel there, they are too poor."

To improve this situation, the project uses community meetings to raise awareness of the signs, symptoms and treatment for TB. Health workers and volunteers are trained



to collect and transport sputum samples to the nearest testing centre for TB diagnosis.

Open TB meetings like the ones Kanduri attends are a place for people to find out more about TB and voice any concerns they have. At the forum where these photos were taken one of the questions asked was, "Where do we get the TB medicine from?" The process of Directly Observed Treatment (DOTs) was explained. This is where a trained health worker or volunteer monitors daily pill taking for TB patients. People concerned about their health have time to speak to someone from LEPRAs at the end.

Kanduri attends the meetings which are held by LEPRAs across villages in his area. He wants to show others that TB is curable.



Kanduri on his bike: Being cured of TB means that 76 year old Kanduri can easily cover 50 to 60 kilometres on his bicycle. Before LEPRAs came to his village he could hardly get out of bed.

Extending our influence through approaches that work...

LEPRA's work to improve health care goes hand in hand with advocacy work. Here the aim is to influence public policy and improve practice, based on our own evidence based models of best practice and research results.

LEPRA works in partnership with government and communities to implement long term solutions to immediate health issues. The ultimate goal of LEPRA's partnership with government is the eventual handover of services and the uptake of best practice into the government mainstream. This process is facilitated by training and capacity building in government health system management at a local and state level.

In 2011/12 LEPRA provided technical support to state leprosy programmes through LEPRA technical resource units in Odisha, Andhra Pradesh and Madhya Pradesh. Significant progress towards sustainable leprosy services was made in 2011/12 with the handover of LEPRA JUNLEP referral centre in Odisha to government for their continued provision of services.

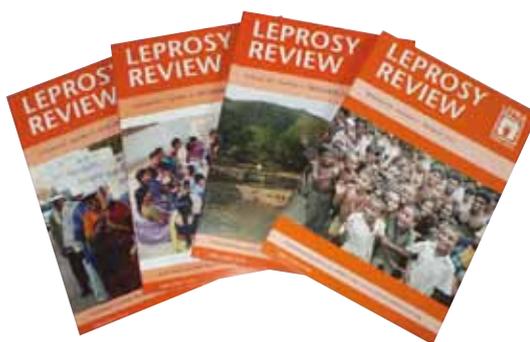


LEPRA's leprosy referral centre model of best practice was adopted into the World Health Organization's Disability Prevention and Medical Rehabilitation Guidelines on leprosy for implementation in the Government of India five year strategy. This will improve future government provision of leprosy services for those affected.



LEPRA's Blue Peter Public Health and Research Centre continued laboratory and field based research on leprosy, TB, lymphatic filariasis and HIV. This resulted in the publication of five research papers and articles in Indian and international journals, which will contribute to increased knowledge on these diseases.

Physiotherapy is an essential part of leprosy care. In a step forward for the provision of leprosy services, 14 LEPRA trained physiotherapists were absorbed as contractual staff in the Government of Odisha's Health Department.



Leprosy Review: LEPRA continued to publish Leprosy Review, the only English language journal on leprosy research. Four issues were published, including a special issue on leprosy and stigma. This publication is a key tool in sharing leprosy research and informing policy and best practice.

LEPRA's Sputum Collection Centre model was adopted as best practice into the Government of India Revised National Tuberculosis Control Programme guidelines for 2012-17.

In Bihar an evaluation team from the National AIDS Control Organisation and State AIDS Control Societies recommended LEPRA's Targeted Intervention for Injecting Drug Users project as a model project for the state.

Standing together we reduce inequality and prejudice...

Central to the impact LEPRAs makes is changing perceptions, reducing prejudice associated with disease and poverty. Prejudice, that would otherwise damage lives and hamper life-chances.

"It is harder to crack a prejudice than an atom."

Albert Einstein.

Changing behaviours takes time but we continue to do so.

Some of the ways LEPRAs assisted people affected by leprosy to fight prejudice they face include:

- **Providing assistance to access the welfare schemes and disability allowances to which they are entitled. This support has improved the economic status of 397 people and their families in India.**
- **Successfully advocating for the rights of people affected by leprosy and to fight to remove discriminatory laws in India, Bangladesh and the UK.**
- **Ensuring the voices of leprosy affected people are heard.**

In a landmark victory, LEPRAs was part of a group which successfully achieved for the repeal of a law in India which will stop the practice of children with leprosy from being separated from other infants in children's homes.

In Bangladesh LEPRAs staff were part of the committee which achieved a change in a discriminatory law which prevented people affected by leprosy from entering health centres and hospitals.



Marte and Lily sign our petition to end leprosy discrimination. Picture courtesy of Evening Gazette, Colchester, copyright retained.

LEPRAs ran a 'Humanity in Action' campaign based at the University of Essex to draw attention to discriminatory policy towards people affected by leprosy entering the UK. Following this and other campaigns the Home Office and UK Border Agency acknowledged the need to change their medical guidelines in relation to leprosy. A Home Office spokesperson confirmed that having leprosy is not valid grounds for refusing a visa or entry into the UK.

LEPRAs India advocated for the inclusion of members of State Coordination Committees onto the National Forum of Leprosy Affected Persons. We provided office space, supported them in mobilising resources and advocated for their rights and entitlements. This means is that people at grassroots will have a voice at state level in Andhra Pradesh, Madhya Pradesh, Odisha and Bihar.

After being contacted by a number of leprosy affected people, LEPRAs initiated a successful campaign to get a misleading leprosy scene removed from an Aardman Productions/ Sony Entertainment animated film released in 2012. Aardman Productions issued a statement saying "After reviewing the matter, we decided to change the scene out of respect and sensitivity for those who suffer from leprosy. The last thing anyone intended was to offend anyone and it is clear to us that the right way to proceed is to honour the efforts made by organisations like LEPRAs and the World Health Organization to educate the public about this disease." The public debate generated brought the issues of leprosy and discrimination to a much wider audience.

Stephen Fry tweeted in support of LEPRAs, "LEPRAs will tell you that leprosy is a desperate condition." Your help means that we can make sure it is not.



LEPRA is the catalyst, people make the difference...

In a small dusty village in Southern Odisha, four women sit together in the shade of a tree outside a small blue painted village hall. As part of the LEPRA SAHYOG project, these local women are now four local life-savers.

Together these four women work together to form a chain that links more than 4,100 people in the rural villages that surround this one with life-saving TB diagnosis and treatment.

The first two in the chain are the government health worker (Niru Pamasudhansu) and maternal and child health worker Meena Kumar Nayak. Together they go door to door educating people on a number of health conditions including TB. They also run the sputum collection clinics which now take place in the village hall on the first and third Wednesday of every month.

Sputum samples are then given to volunteer health activist Sanjukta Kumari Gouda. She put these in a special bag provided by LEPRA. She then cycles the 10 miles to the nearest government TB testing centre on a bicycle from LEPRA with her small daughter Grace sitting in a basket.

Sanjukta waits at the centre, returning with a diagnosis and any medication for positive cases. These people are then visited by project volunteer K. Maleswari, who explains:



"I go directly to the patient's house and tell them that they need to take the treatment. I tell them on which day they will take it and I sit with them while they take it. I give only one dose at a time, take back the empty pill strip and record it."

She holds up the treatment card and shows everyone watching the empty pill strip in her hand. She told us:

"Before LEPRA, people died from TB. Now they can be treated and they live."

From left to right Niru Pamasudhansu (government health worker), Meena Kumar Nayak (government 'Anganwadi' maternal and child health worker), Sanjukta Kumari Gouda (volunteer health activist) and K. Maleswari (community volunteer).



180:
the number of TB sputum collection centres like this established in this project

2,272:
the number of community volunteers LEPRA trained last year

4,100:
population that just these four life-savers serve

11,488:
the number of health workers LEPRA trained last year

The kindness of strangers...

Funding and fundraising determine the degree to which we are able to impact on lives for the better. The financial support we receive in the form of grants, donations, gifts left in wills and in memory of friends and family means that we are able to continue and extend our work to those living on the margins of society.

This year's annual review covers the 12 month period between April 2011 and April 2012. Despite the difficult economic climate, financial support we received from the general public remained largely unchanged.

During this year, for every £1 we spent on our fundraising activities, we raised £4 from the public.

We thank you, our individual supporters, fundraisers and advocates. The financial support we receive from donations, gifts and sponsorship by individuals, fundraising by groups and schools makes our work possible.



Despite lashing rain and winds 700 hardy cyclists took part in our annual Edinburgh to St Andrews cycle ride and raised £34,000 for LEPRAs.



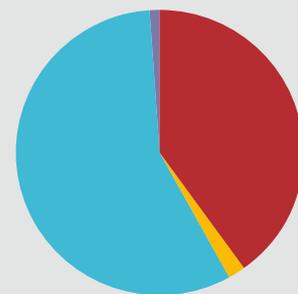
'Namaste' Celia on her fourth LEPRAs charity bike ride in India. We have introduced a new November India bike ride route in Madhya Pradesh, known as the 'Heart of India'. This complements our existing ride which takes place in the coastal state of Odisha each January.

We thank Trusts and statutory grant makers for their backing. The cycle of statutory funding meant that we were not able to leverage quite as much as last year. We expect this situation to improve as funders find themselves in a position to invest once more.

A number of projects came to a sustainable end. LEPRAs HIV Counsellors Project in Andhra Pradesh, India was handed over to the state government in 2011. This project has been providing quality counselling services to people visiting HIV care centres across the state of Andhra Pradesh since 2003, in the process reducing the prevalence of HIV infection. The transfer of this £1 million project is a positive step forward towards sustainability and is reflected in our reduced income.



Total income for 2011/12: £5.4 million*



- Public support – 58%
- Trusts and businesses – 3%
- Statutory grants and income from charitable activities – 38%
- Sales, investments and other income – 1%

*12 month period

Why leave a gift to LEPRAs?

Last year we reached more than 1.7 million people through our work. One in five of these people are helped through gifts made to us in wills.

A gift in your will is one way you could ensure that people affected by leprosy and other diseases of poverty continue to be helped into the future.

If the time is right for you now, we would be most grateful if you would consider including a gift to LEPRAs in your will, after providing for friends and family. If you already have a will, it is a straightforward process to add a gift to LEPRAs should you so desire.

Pupils at Lavington School Wiltshire joined children from 790 schools across the UK and British Isles who raised more than £658,000 for LEPRAs in 2011/12.

...touches lives and changes them forever

In 2011/12 we rebuilt our organisational reserves, enabling us to plan for the future with confidence.

LEPRA's India programmes focussed on four states: Andhra Pradesh, Madhya Pradesh, Odisha and Bihar. In Bangladesh LEPRA's programmes focussed on TB and leprosy control and treatment, targeting four districts in the north west of the country, Bogra, Sirajgonj, Natore and Pabna.

Bringing about lasting improvements in health services LEPRA continued to go beyond providing direct services, to build the understanding of government and capacity of health workers.

In addition to providing direct services through our referral centres, technical resource units and laboratories LEPRA trained 13,000 government health staff, increasing their capacity to respond to the health needs of the local population in the long term and increasing numbers of community-based referrals to health centres.



Capacity building means better skills for leprosy diagnosis, treatment and follow-up. Better skills and capacity will help make preventable disabilities like the ones Arjun must live with a thing of the past.



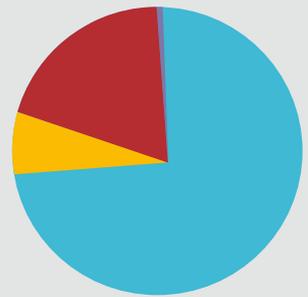
LEPRA reached more than 36,000 people in India with eye screening and eye care services, a third were children.

LEPRA also trained 2,272 community volunteers who work to mobilise their communities on health issues, increasing health seeking behaviour.

In addition LEPRA trained 2,928 unregulated and undertrained private health practitioners and village doctors helping them provide appropriate and better quality care to those people who often have no other choice in accessing health care.



Total expenditure for 2011/12: £4.8 million*



- Projects and programmes – 74%
- Research, education and other charitable activities – 7%
- Fundraising – 18%
- Administration and governance – 1%

*12 month period

300 women were trained in tailoring and embroidery in LEPRA's Cairn sponsored community health project AROGYA DISHA in India. Monthly income increased by 1,500-2,000 Indian Rupees (£20) for 60 per cent of the women and their families.

Visceral Leishmaniasis is a deadly disease that is spread by the female sandfly, which lives in the walls of mud huts. This little girl is just one of many children in one of the villages we cover in Bihar who have Visceral Leishmaniasis. Village elders thanked us saying, 'you have saved our children's lives by working here'.

How you have helped: Bhola's story



Imagine being disabled by leprosy as a young child because you weren't treated in time. Something as simple as turning the pages of this review would become increasingly difficult and eventually impossible.

Imagine your confusion as your fingers began to curl and become stiff. You find it hard to walk because something is wrong with your ankle, your foot drags and you can no longer lift it. Children at school tease you because you often fall over. They say your hands look strange; no-one will sit next to you in class.

This was life for 12-year-old Bhola from Bihar in India. When we first met Bhola all he wanted to do was hide away. He could do very little for himself. Bhola will need reconstructive surgery but can't have this until his body is more developed.

Until we can refer him for surgery LEPRA is helping Bhola, providing care and support, special shoes to help him walk and teaching him physiotherapy exercises to strengthen his hands.

When we caught up with Bhola a few months later at the LEPRA Munger referral centre in Patna, Bihar, it was like meeting a different child. Full of smiles he confidently showed us his special shoes and talked about his physiotherapy exercises.

When we talk about the impact we make, we are talking about people like Bhola, about their lives and their futures. You have helped bring smiles like Bhola's to 700,000 individual faces, each one a life we have changed together.

Thank you.

Bhola's smile lights up the room, it is lovely to hear him laugh again.



Bhola writing: Physiotherapy exercises are helping Bhola to write.

You Tube
Broadcast Yourself™

Visit us on YouTube to view a short film of Bhola talking about his life and LEPRA at www.youtube.com/LEPRAHinA

LEPRA Health in Action
28 Middleborough
Colchester CO1 1TG

Registered Charity Numbers:
213251 (England and Wales)
and SC039715 (Scotland)

A company limited by guarantee
Registered in England No. 324748

Patron Her Majesty The Queen
President Sir Christian Bonington CVO, CBE, DL

Photo credits: Colin Summers Photography,
LEPRA Health in Action

T: 01206 216700

F: 01206 762151

E: fundraising@leprahealthinaction.org

W: www.leprahealthinaction.org



LEPRA
healthinaction

Follow us on:



@LEPRA_HinA