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Pages 4 & 5

# LepraNews

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We will beat leprosy together

Patron: Her Royal Highness Her Majesty The Queen  
Vice President: His Royal Highness The Duke of Gloucester  
KG GCVO

## In this issue

.....

India's urgent need for COVID-19 testing and vaccination support

Remembering His Royal Highness The Duke of Edinburgh

.....

## Lepra remembers

# His Royal Highness The Duke of Edinburgh

1921 - 2021

The Duke of Edinburgh was a long standing supporter of Lepra, along with Lepra's patron Her Royal Highness, Her Majesty the Queen. In the past, the Duke of Edinburgh supported Lepra's Child Adoption Scheme, sponsoring children affected by leprosy in Africa. This scheme enabled children to receive treatment and continue their education, thereby enabling them to pursue independent and fulfilling lives.

Lepra's Dr. Doug Coffin, writing from the Itu settlement in 1940, said of the Child Adoption Scheme, supported by the Royal Family, "A child, if they are to grow into a healthy adult, free from any major complexes, needs to be brought up in the company of other children, to experience kindness from their elders, receive education and not suffer anxiety about their shelter and food."

In 1956, during the Royal visit to Africa, Her Majesty and the Duke of Edinburgh met with many people affected by leprosy. The Duke was notably warm, sympathetic and supportive of all those people he encountered, including a young boy he

sponsored.

The Duke and Her Majesty also supported the building of new children's homes in Nigeria, where children affected by leprosy could live and receive treatment, care and education. During his visit to Lepra's programmes in Africa, His Royal Highness took a particular interest in the scientific advances following from Lepra's pioneering use of Dapsone as the first cure for leprosy.

Lepra's longstanding and historic relationship with the Royal Family began in 1924, with the Prince of Wales inaugurating Lepra at Mansion House in London, and King George VI becoming the first patron in the same year. When Her Majesty, Queen Elizabeth, took her father's place as patron of Lepra in 1952, the relationship flourished and it continues to be an important part of Lepra's history to this day. The passing of His Royal Highness the Duke of Edinburgh is a sad loss in the fight against leprosy.



*The Duke of Edinburgh visiting a leprosy settlement in Oji River, Nigeria*

## The Barry Copeland Trust: Bringing forth hope from tragedy

In the words of longstanding Lepra supporter, Barry Copeland, The Copeland Family Trust "has arisen like a phoenix from the ashes" of his beloved family.

Tragically, in 2008, Barry's wife, Ann, and his two daughters, Ciara and Niamh, died in a car crash. At the time, Barry requested that they be remembered by donations to charity rather than flowers. However, he was totally unprepared for the consequent inflow of funds.

Remembering that both Ciara and Niamh were enthusiastic fundraisers for Lepra through their primary school, St Margaret's RC Primary School, Montrose, Barry was able to donate a staggering £10,000, a sum that was then doubled by the incredibly generous sponsorship he received after running the Cape Wrath Marathon (his wife's favourite place) four months later. Since then, The Copeland Family Trust has donated at least £5,000 annually to Lepra, and Barry's fundraising efforts have continued to this day, with most years seeing him or a fellow Trustee undertake a sponsored challenge. Last October, Barry raised

a fantastic £3,117.83 for the Trust by cycling more than 1,000 miles, and ascending more than 100,000 feet in the process!

Since its inception, funds from the Copeland Family Trust have specifically supported Lepra's work at the Koraput Referral Centre, which he visited in April 2011 and unveiled a commemorative plaque. More recently, the Trust's funds have been directed to the wider Swabhiman project which includes Lepra's work in Koraput District and other highly endemic districts of the state of Odisha. For more than a decade, Lepra has been able to provide people affected by leprosy in this region with treatment and support, including physiotherapy to treat nerve function issues, and care and treatment for ulcers and leprosy reactions. Our staff also carry out diagnoses, alongside counselling and outreach services.

The Copeland Family Trust's ongoing support for our work is a fitting tribute to the memory of Ann, Ciara and Niamh. Helped by Barry's efforts, Lepra has been able to bring hope to people affected by leprosy in one of the poorest and least developed parts of India.

## Focus on history

Lepra initially became involved in Bangladesh, then referred to as Bengal, in the late 1920s. The first Lepra voice in the archives from Bangladesh is that of Dr Ernest Muir, featured in our primary edition of *Leprosy Review*, then called *Leprosy Notes*, in 1928. Dr Muir was based in Bangladesh and he identified the main factor contributing to the fast spread of the disease which was lack of doctors trained to diagnose leprosy. In 1928, there were already well established hospitals and clinics across the region, including many doctors and nurses, but so little was known about leprosy that it was rarely recognised and therefore, continued to spread undiagnosed. People affected by leprosy remained neglected, developing severe disabilities and reactions, and were often left destitute and discriminated against.



*Dr Ernest Muir*

Dr Muir immediately began to try and rectify these issues. However, with very little funding at his disposal, a meagre annual budget of Rs 4,000, around £34 now, he had to be careful with his approach to leprosy treatment and ensure it was sustainable. Dr Muir had a difficult task ahead of him, to train leprosy specialists in the diagnosis and treatment of the disease without

any infrastructure, for example specialist clinics or hospitals. His plan involved recruiting a specialist, who trained doctors and nurses in the region, who in turn became district advisers and local experts.

This "train the trainer" approach remains highly effective today, with Lepra successfully securing £650,000 from the Department for International Development in 2020 to upskill health workers in delivering morbidity management and disability prevention services to people affected by lymphatic filariasis in Bangladesh. In addition, this seven month programme raised awareness of the disease through advocacy, planned communication opportunities and the development of a range of information and education materials shared within communities.

While in Dr Muir's time, such a high level of education and training was considered ambitious, it has become a staple of Lepra's approach to helping people. This bold, but necessary, plan would enable medical professionals to set up

## Fighting leprosy in Bangladesh

and run their own leprosy clinics to diagnose and treat people across the region. Dr Muir also began a survey of each district in Bangladesh to locate people affected by leprosy and test their families and communities. The initial plans were so successful that Lepra supported five further survey officers to assist the team working across a five-year period in the leprosy clinics. The process continued step by step: after setting up a clinic and reaching out to people affected by leprosy, training was given to local medical workers as was advice to district authorities on how to proceed.

Dr Muir said, "It is hoped that the existence of such clinics and the results obtained by treating people affected will lead to other centres being started, and to medical practitioners in the neighbourhoods attending clinics and treating patients."

A man of great vision, Dr Muir, together with Lepra, helped leprosy be seen as a treatable disease just like any other, and not a life changing condition, creating a purposeful drive of active treatment and research. He also considered the whole picture of the person affected: their social conditions as well as their medical issues.

Dr Muir continued, "There is no section of the community which deserves by right more thoughtful care and consideration than those afflicted with leprosy. Now that we have the knowledge, if this care and consideration is withheld, judgement will surely fall upon those responsible."

Lepra has continued this effort against leprosy in Bangladesh since Dr Muir's intervention, and currently operates in 19 districts across Bangladesh with its pluralistic healthcare system and significant shortage of physicians, specialists and clinical equipment, most of which are concentrated in urban areas. Inequality also affects healthcare in Bangladesh and limited government funding results in high costs to the individual.

There is an estimated patient-doctor ratio of just **6 doctors per 10,000 people**, according to the most recent (2019) health bulletin produced by the government of Bangladesh. Lepra is committed to improving the lives of people affected by leprosy and LF through targeted programmes, as well as the strengthening of existing government healthcare systems. The groundwork laid in the 1920's is still being used to beat leprosy in the 2020's!

# COVID-19 EMERGENCY VACCINATION APPEAL

## VACCINE INEQUITY

LOW-MIDDLE INCOME COUNTRIES ARE STRUGGLING TO ACCESS ADEQUATE SUPPLIES. LEpra URGENTLY NEEDS YOUR HELP TO PROVIDE LIFE CHANGING ACCESS TO COVID-19 TESTING AND VACCINATIONS.

**£19**

provides one vulnerable person with both COVID-19 vaccinations. This includes all associated travel, equipment, and awareness costs of reaching isolated people in isolated locations.

**India** India remains the worst hit country in the world, with almost 400,000 known cases being reported a day and deaths rising steadily. This is not a second wave; it is a tsunami. Throughout the past year, Lepra has worked incredibly hard conducting PCR tests at the Blue Peter Public Health and Research Centre (BPHRC) in Hyderabad. Staff at the centre have been providing free tests for people affected by leprosy and lymphatic filariasis, and cheaper tests for others in the local community. Currently, Lepra is recording anywhere from 35-40% positive results per 140 tests a day, compared to the current UK rate of between 0.21% and 2.2%. This huge increase in positive cases is a cause of great concern for Lepra and our staff overseas, who are at the frontline of the pandemic.

2021 in Patna. Thereafter my wife became unwell and needed oxygen and a lot of health care. Unfortunately, no doctors or other health staff were able or willing to assist and those that in the end did so, charged three times as much as normal for health services, creating family financial hardship," said Kamalesh Chandra Lal, a Lepra colleague in India.



The country's health system is at breaking point. We urgently need your help to deliver our vaccination project across India.



Lepra's vaccination project has already begun in Bihar and Andhra Pradesh, with the plan to upscale in the coming weeks and months. Vaccines are vital. They remain the best weapon the world has against COVID-19, but with fewer than 10% of the Indian population vaccinated, there is an urgent need for support. We are working around the clock to vaccinate the most vulnerable in the hope that it will lessen the severity of symptoms if people do catch coronavirus in

the coming weeks and months.

COVID-19 presents a rapidly developing global situation. It is evident that the more cases there are, a greater number of mutations will occur. Healthcare professionals are in agreement that vaccinating will slow the rate of mutations, reducing their chance of taking hold and spreading.

Our best chance to beat COVID-19 is to pull together and vaccinate the world.

You can help those most vulnerable, those most at risk, by donating today.

**Just £19 allows us to provide someone with leprosy both doses of the vaccine in a safe and dignified location. By donating today, you can help us plug the gap in India's collapsing health system.**

## Bangladesh

The COVID situation in Bangladesh, while not as severe as India, remains a serious concern with cases and deaths rising each day. For Lepra staff, and those in their care, this has meant no travel, and, for some, a loss of income due to business closures.

A significant number of people affected by leprosy and LF have not received a vaccine, especially in rural areas. The reliance of the government on technology to register people for vaccination appointments has meant that those in rural areas or those without the ability to use the internet or telephones have been left behind. Throughout June 2021, Lepra will begin to vaccinate 2,000 of the most vulnerable people affected by leprosy against COVID-19.

The lockdown has created a new wave of fear and uncertainty for the people Lepra helps, with many facing precarious financial situations and some unable to care for themselves or their families without support. A significant number of the people Lepra helps, work as day labourers, farmers or small goods traders and they have been severely impacted by the lockdown and the worsening COVID-19 situation. Lepra is working to provide nutrition support to these people. **To buy a family food, it costs just £21 a week!**

The second wave of COVID-19 has also caused a big increase in the need for basic medical supplies, like oxygen and ventilators and there is an urgent need to expand healthcare facilities across the country. While our staff are vaccinated, Lepra has also been providing Personal Protective Equipment (PPE) to them so that they can continue their work safely.

**£21 provides a week's worth of food for a vulnerable family.**

Overall, the situation is bleak and set to get worse. Hospital admissions are at dangerous levels, with the Health Minister fearing lack of resources. Private hospitals have been urged to offer their beds and share supplies with public hospitals to help slow the rate of infection. In April, a specialist COVID-19 hospital opened in Dhaka, catering to 1,000 patients at any given time and easing the pressure on the healthcare system.

Despite these challenges, Lepra is committed to continuing its vital work for people affected by leprosy and LF. **Your support will enable us to weather the storm and help some of the most vulnerable people in society.**



"Our work hours are very long, but we cannot stop. We test every person who comes to us, we turn no one away," said Dr Aparna Srikantam, Head of Research at BPHRC. Dr Srikantam is leading the charge on COVID-19 testing, but remains deeply concerned by the threat to Lepra staff because, despite vaccination, they are falling ill. On any given day, 4% of our vital frontline staff are off work because of the virus. They are concerned for themselves, their families and India as a whole.

"My older brother died in Delhi. When visiting there we found twelve other family members with COVID. Then my nephew died on 15 April

## What happened to India's vaccine drive?

COVID-19 cases in India are on the rise as vaccinations lag. Demand has far outstripped supply. Complex online registering platforms are dividing vaccine access, with only those who can access the internet able to get an appointment, and even that does not guarantee a dose due to supply issues. Lepra's COVID-19 testing and vaccination outreach projects are vital in providing access to healthcare to the vulnerable, who would severely struggle otherwise. Help Lepra to reach **the forgotten rung, those at the bottom of the health system!**



**Please donate or become a regular giver today!**

 [donate.lepra.org.uk](https://donate.lepra.org.uk)

 Return the donation form enclosed

 Call 01206 216 700

 Text LEpra followed by donation amount to 70500

## An interview with Dr Charlotte Roberts

In 2020, archaeologist and Lepra supporter Dr Charlotte Roberts, who specialises in paleopathology and bioarchaeology, published her book 'Leprosy Past and Present', offering a unique insight into the historical treatment of leprosy.



Paleopathology encompasses the study of disease, both human and non-human, while bioarchaeology involves the study of biological materials, such as human remains, to better understand human life and the environment in which humans lived in the past. Lepra spoke with her about her work and her enduring research into leprosy, past and present.

### Why did you first become interested in leprosy, in particular as a bioarchaeologist?

It has been a fascinating journey for me and has involved visiting leprosy hospitals in India and Nepal, and the islands of Molokai in Hawaii and Spinalonga in Crete, where people with leprosy were isolated in the 19th and early 20th centuries. I was also privileged to attend two leprosy congresses. At these congresses in Brussels and in Beijing, I was overwhelmed by the amazing work so many people are doing to help people with leprosy today and the continued efforts to reduce/eliminate stigma.

### Having studied the history of the disease, what do you find the most fascinating or difficult aspect of the disease?

While leprosy is a clinically defined disease, it is also very much a "social" disease and it is perhaps the latter that I find so interesting, including the variation in how people in different parts of the globe, past and present, have addressed and are addressing this infection. I hope my work will provide the long view of leprosy, and also give people with leprosy in the past a voice to tell their actual stories that are untainted by misconceptions

For the full interview with Dr Charlotte Roberts, please check out our website [lepra.org.uk/news](https://lepra.org.uk/news)

### Victoria Hislop releases Maria's Island

Lepra ambassador and best-selling author, Victoria Hislop, returns this summer with her first ever children's book. Maria's Island revisits the characters from The Island and centres around Maria, a girl living in the Cretan seaside village of Plaka, across the water from the leper colony on the island of Spinalonga. She knows little about leprosy until it touches her life in a terrible way when her mother, and her best friend Dimitris, contract the disease and are sent to isolate on the island. A few years later, when Maria is herself diagnosed, she must also face the prospect of leaving everything she knows to journey to Spinalonga. But with advances in medicine, hope may be just around the corner. Maria's Island is complete with illustrations from Gill Smith and will be available to buy from 3rd June 2021.

### John Bradburne's 100th birthday

Forty-one years after the death of John Bradburne, Mutemwa Leprosy Care Centre is now home to 34 people, 19 of whom are affected by leprosy and 15 who are destitute. Mutemwa is the only leprosy centre in Southern Africa and cares for people physically and mentally. In 2019, Lepra and John Bradburne Memorial Society (JBMS) signed a Memorandum of Understanding to develop the Mutemwa Leprosy Care Centre as a model for best practice in the treatment and care of people affected by leprosy.

Lepra is also providing specialist shoes to the centre, enabling people affected by leprosy to regain some of their independence. The shoes are custom made, and each person received 2 pairs, helping restore their independence. Please visit our website for further details: [lepra.org.uk/where-we-work/zimbabwe](https://lepra.org.uk/where-we-work/zimbabwe)

This year, JBMS is celebrating John's 100th birthday. To commemorate this, a major Centenary celebration is being held at The Holy Name Church in Manchester on the 25th September 2021. This will be a once in a lifetime event, where John's poems are being set to music by world class composers and will be premiered during the event. For more details visit [lepra.org.uk/projects/zimbabwe/mutemwa-leprosy-care-centre](https://lepra.org.uk/projects/zimbabwe/mutemwa-leprosy-care-centre)



John at Mutemwa

### A Marathon A Month

Lepra's challenge ambassador, Tom Barton, is running a marathon a month for Lepra. He is aiming to run a staggering 1,800 miles in total, that's the width of India!

Since becoming a supporter, Tom has raised over £25,000 and has completed a total of 18 marathons. He said, "Who knows what this year will hold but I thought setting myself the challenge of running a marathon (or more) each month would be a good place to start! As well as fundraising, this year long challenge aims to keep undiscovered illness and disease, such as leprosy, at the front of mind. I'll be aiming for 1,800 miles in total, the width of India!" If you would like to support Tom on his Marathon a Month challenge, visit our website [lepra.org.uk/news](https://lepra.org.uk/news)

With lockdown and homeworking increasing the incidence of sedentary behaviours, health officials across the world have been advocating the importance of undertaking activities that support the improvement of both mental and physical health. To that end, we want to encourage you to "Move for Lepra". By choosing to walk, run, skip, hop, cycle or swim, you can set a personal or group goal you want to achieve. Visit [lepra.org.uk/events/detail/move-for-lepra](https://lepra.org.uk/events/detail/move-for-lepra) for more details.

Lepra also has coveted London Marathon 2021 places in both the virtual and physical event! Do you fancy being a part of Team Lepra 2021? We'd love to hear from you! Visit [lepra.org.uk/events](https://lepra.org.uk/events)



£3 a month can pay for a community to be screened for leprosy and detect up to 50 new cases early!

## Regular giving makes such a difference!

Regular gifts play a vital part in our work to beat leprosy. Here are 5 reasons to give regularly:

-  The incredible kindness of our monthly givers means we are able to plan future projects to provide long-term, sustainable support to people affected by leprosy.
-  You will help people and their families affected by leprosy receive the right care, at the right time and in the right place.
-  Becoming a regular giver allows you to spread your donations across the year.
-  We will keep you informed through our regular newsletters and progress updates.
-  Regular giving helps to keep administration costs low. Simply fill out the direct debit form enclosed with this newsletter, or set up a regular gift online at [donate.lepra.org.uk](https://donate.lepra.org.uk)

## Rotary Volunteer Expo 2021

Lepra exhibited at the Virtual Volunteer Expo 2021 on the 7th and 8th May. It was a fantastic event, hosted by Rotary, and attended by many wonderful volunteers looking to learn about different causes and new volunteer opportunities. The Lepra stand was fortunate to meet many new people, all of which were concerned to hear leprosy is still prevalent across the globe, and eager to learn more about how they can get involved. Lepra is always on the lookout for new volunteers, and we have plethora of volunteer roles to fill. Visit our website for more details: [lepra.org.uk/get-involved/volunteer](https://lepra.org.uk/get-involved/volunteer)

## THE STORY OF AROTI: A LEpra MENTAL MOTIVATOR

Aroti, a trained social worker, has worked for Lepra in Bangladesh for the past two years. She became involved in Lepra's Mental Motivator Project when it was launched in 2019, and now works as a Mental Motivator at the Khola Mon project, providing support and knowledge to people affected by leprosy and lymphatic filariasis. She also assists with the running of Self Care Practice Groups (SCPG), which were launched across several districts in Bangladesh, ensuring that people affected by leprosy and LF learn from each other to better manage their diagnosis.

Aroti is responsible for teaching self-care to 26 people affected by leprosy and 44 people affected by LF in her district. She provides important information to people, educating them about their conditions and the support services available to them. Aroti also provides home visits, ensuring that people with no means to travel, or people in isolated areas, can still access the support they need. People affected by leprosy and lymphatic filariasis often experience social isolation and prejudice because of their diagnosis. Aroti plays

a key role in promoting social inclusion within the community setting. She is also involved in assisting people with securing economic support and government grants to assist with their daily life.

Over the past 12 months, her work has evolved to encompass helping people within the community at risk of COVID-19 and helping provide emergency food kits to people in need, along with assisting them in securing Disability Cards from the local authority. People working for Lepra, like Aroti, have worked at the frontline of the pandemic for over a year now. Aroti's work with SCPGs and community groups has grown to include advice on COVID-19, including its symptoms and proper hygiene practices to prevent people from getting infected or spreading the virus.



Aroti delivers a counselling session

**"I have been a social worker for many years, but the work I do with Lepra for people affected by leprosy and lymphatic filariasis has been some of the most rewarding in my life."**

**- Aroti**

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### ARE YOU GIFT AID ELIGIBLE?

In December 2020, we encouraged our wonderful supporters to make a Gift Aid declaration. Over the year, we saw a magnificent increase in Gift Aid income, from £87,000 in the financial year 19/20 to £108,000 in 20/21, an incredible 24% increase! If you are eligible for Gift Aid, donate more, without spending more. Visit [lepra.org.uk/get-involved/online-gift-aid-form](https://lepra.org.uk/get-involved/online-gift-aid-form)

LEGACIES OF HOPE.

## A gift in your will is a legacy that lasts a lifetime

Legacy giving makes the world a better place, for generations to come. Our vision is a world free from prejudice and discrimination due to leprosy, and a gift in your will can bring us one step closer to this.

We understand that your loved ones will always come first, but after you have taken care of them, would you consider remembering those most vulnerable, most marginalised, often forgotten, by leaving a gift in your will? Every **third person** we help is because of a gift left in a will.

Leaving a gift in your will is a very personal decision. If you have any questions or would like to receive our legacy guide, please make contact with Olivia Egan who would be delighted to help. Olivia can be reached by email at [OliviaE@lepra.org.uk](mailto:OliviaE@lepra.org.uk).



We will beat leprosy together

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