LepraNews

Summer 2022

lepra
We will beat leprosy together

Bangladesh

A Blueprint of Community Healthcare

Celebrating 70 Years of Royal Patronage

The Importance of Early Case Detection

Sumon's Journey of Recovery and Success

www.lepra.org.uk

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

An Introduction by Jimmy Innes

I have been at **Lepra** for five months now, and am feeling very much at home.

It was an exceptional visit in every way. We spent the majority of the time travelling district-to-district on busy, dusty roads, meeting **inspirational people** and doing inspirational things at every turn.

It was an **unforgettable experience**, and I came back home enthused and imbued with the great work that Lepra does in Bangladesh, along with a heightened understanding of why we do what we do and how we can continue to support as best we can the thousands of Bangladeshi people affected by leprosy and lymphatic filariasis (LF).

In Bangladesh, Lepra works hand-in-hand with the local health authorities, supporting health workers, clinics and hospitals to provide quality services. It's a great approach, **strengthening** the health system itself, rather than running our own clinics and services in parallel. It's an approach designed to enhance the existing infrastructure, leaving a lasting legacy providing support for as long as it is needed.

We met with the lead health administrator in Lalmonirhat District in the north of the country, where Lepra has worked for 10 years. I asked him how helpful the support he got from Lepra was; and he looked me in the eye and said,

"The way I see it, this is our programme, and Lepra just happen to be the ones who are here helping us deliver on it".

It was **music to my ears**, and revealed the deep ownership he had for the leprosy programme. **Sustainability in action**.

Lepra Bangladesh also works with groups and **federations** of people affected by leprosy and LF. Again, it's an excellent approach which **empowers** people to push for full inclusion in society by giving a collective platform to pursue livelihood opportunities, access to essential services and, crucially, to break down pervasive **societal prejudice** against leprosy and LF.

We do this at all levels in rural villages and communities by establishing **self support groups** (SSGs) and at district level by nurturing and developing **representative federations**, registered as organisations in their own right.

We met with the **Bogura District Federation** of persons affected by leprosy, which is made up of 101 separate SSGs from all corners of the district, and which is a model federation for other districts to aspire to. Lepra has been working with them for 10 years now.

At the meeting, the members told me that **75%** of all suspected cases of leprosy in Bogura district are being referred to the health clinics by the federation members themselves, through their networks and knowledge within their own communities.

This is so **powerful** and clearly demonstrates how a mobilised and active team of people affected by leprosy can really help our collective drive to ensure more active and early identification of leprosy cases. This will ensure that people get access to treatment and support which will help them reduce the prejudice and disability as a result of leprosy.

You can read more about these approaches in this edition of Lepra News. I hope you enjoy it!

Lepra is a non-governmental organisation (NGO), and has been working to find and assist people affected by leprosy since 1924.

Since that time, Lepra has had two defining characteristics Firstly, we are secular. A positive decision to favour no one and everyone. Secondly, we prioritise being evidence-led.

Leprosy is a communicable disease, caused by bacterium, which affects the skin and peripheral nerves of people. It can result in severe disability, prejudice and even cause blindness. Leprosy and LF remain two of the least understood and most widely ignored diseases in the world. Millions of people are affected, with numbers continuing to rise. If left undiagnosed or untreated, leprosy and LF can cause life changing disabilities.

Leprosy can incubate in a human anywhere from 6 months to 20 years. As a result, it is often difficult to diagnose the disease until it has already caused severe damage.

Working in India and Bangladesh, we find, diagnose, treat and rehabilitate people with leprosy. Specialists diagnose leprosy using skin test patch anaesthesia, skin smears and non-invasive sensory investigation.

We also work tirelessly to fight the prejudice and discrimination they face in their daily lives.

Our Vision is a world free from prejudice and disability due to leprosy.

A Blueprint of Community Ownership

Bangladesh is a priority area for Lepra in our fight against the spread of leprosy and LF. As one of the poorest and most densely populated countries in the world, there is a serious lack of access to essential health services, which can leave the most vulnerable members of society trapped in a **cycle of poverty and ill health**. Lepra works across the country, in areas identified as most at risk.

There are five strands to Lepra's work in Bangladesh; prevention, detection, treatment, disability support and inclusion. Key to the sustainability of Lepra's work in Bangladesh, is the involvement and empowerment of the **local community**.

Building on the success of the 401 community SSGs, Lepra supports 7 district federations and 36 sub-district federations across Bangladesh which have been formed by people affected by leprosy which gives a powerful, united voice and ownership of healthcare in their district.

In partnership with the Sasakawa Health Foundation, The **Bogura Federation** was formed in 2014 and now serves as a blueprint of best-practice across the country. The federation plays an important role in strengthening the capacity of SSGs, increasing access and uptake of services and helping to alleviate the economic impact of leprosy and LF. Since 2016, the federation has also supported the local health system and National Leprosy Programme in early case detection. Since the involvement of the federation, case detection in the district has **doubled**.

In March, Jimmy and Maria met Golapi, a member of the Padma SSG in Bangladesh.

Golapi started showing symptoms of leprosy about 10 years ago, with white patches appearing on her body and sores developing on her feet and legs.

Her husband died in 2012, leaving her to care for their son and her elderly father. As her condition deteriorated, Golapi was unable to continue working as a farmer so was forced to look for different work which resulted in her struggling to support her family. Her son was unable to continue in school.

Getting involved in her local **SSG**, Golapi was taught vital self-care techniques, which helped her improve her **physical health**. Within the group she also found **emotional and financial support** from her peers. With the help of the local federation, Golapi was also able to find new ways of supporting her family, including becoming involved with a community led fish farming initiative, giving her a chance to learn new skills and become financially self-sufficient. **Golapi** now no longer struggles to find food or clothe her family, and has a greater sense of **optimism** for the future.

Meet **Maria**

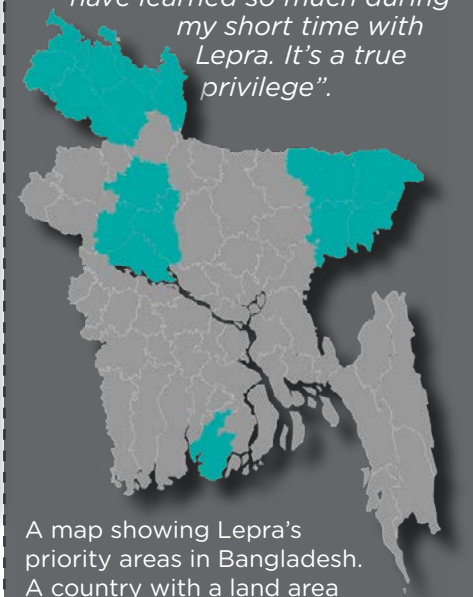
Maria del Mar Marais joined Lepra in December 2021 as Programme Manager for Bangladesh.

She holds a Europubhealth+ Joint Master in Public Health and is specialised in Health Promotion and Community Health.

Before joining Lepra she worked in the humanitarian aid response of the Syrian crisis in Turkey, Lebanon, Iraq and Jordan.

Maria with Runa, President of Maksuda's SSG

"Working with Lepra brings together my passion for working in healthcare at a community level with the expertise in health system and federation strengthening of the Lepra team in Bangladesh. I have learned so much during my short time with Lepra. It's a true privilege".



A map showing Lepra's priority areas in Bangladesh. A country with a land area similar to England and Wales, but holds three times the population. The geography of Bangladesh makes the country highly prone to natural disasters. Each year two thirds of the country suffers from flooding, cutting thousands off from essential health services.

The Importance of Early Case Detection

Globally, there are over **200,000** new cases of leprosy detected each year. However, research suggests that more than 3 million people across the world remain undiagnosed.

The aim of Lepra's approach is to help control leprosy by detecting cases early and so reducing transmission and disability.

Leprosy case detection campaigns use a methodology called **Active Case Finding** (ACF). ACF takes place when a leprosy diagnosis has been made. This door-to-door approach, encourages everyone within that local community to be examined by experienced and trained staff.

Lepra's community SSGs are increasingly playing an important role in early case detection. Members of the community are often able to provide support to our ACF programmes, providing informal education and building trust with people in **remote and rural areas**, helping our teams to locate and refer potential new cases at an **even earlier stage**.

Lepra has found that for every identified case in a local healthcare leprosy case detection campaign, there were two cases missed. These missed cases were often women and people belonging to scheduled castes and tribes in hard-to-reach villages.

The key feature of ACF is finding possible cases and referring them to a specialist who is able to diagnose cases using a **slit-skin-smear test**. Upon diagnosis, antibiotics are then administered to treat the disease and other medicines can be prescribed for reactions, neuritis and any other problems that may occur.

Each person will have their **individual needs** identified and addressed. Services routinely available include morbidity management, disability prevention, complication management and the provision of customised disability appliances..

Lepra's **holistic approach** to healthcare addresses the individuals physiological, psychological and socio-economic needs resulting from a leprosy diagnosis. This **tailored** approach consistently results in the physical recovery through the improvement of people's adherence to the often complex and long term treatment.

In April, Jimmy Innes invited the inspirational Dr David Pahan, Country Director of Lepra Bangladesh, to take part in a fascinating and in-depth podcast, detailing Lepra's approach to the democratisation of healthcare in Bangladesh.

During the interview, Dr Pahan discusses the birth of the Bogura Federation and how the recognition of this community led movement, has become an influential part of Bangladesh's healthcare system, from the national level, through to regional healthcare provisions. The federation now has a powerful voice which plays a vital role in health system strengthening, providing their insight and expertise across the region and even at international conferences.

In March, Jimmy accompanied Dr Pahan to an extended contact tracing event in the Kurigram District. The local clinic had identified two leprosy cases within a single household, which activated a community event to identify further, potential clusters. Two days prior to the event, the federation provided information and education to the community, to help allay fears, and promote the benefits of early treatment. When the clinicians arrived, much of the groundwork had already been laid, with many people coming forward to engage with the team and seek support and referral options.

The proactive approach of Lepra's ACF, with support of the community led federations, helps countless people receive life-changing care and avoid unnecessary disabilities. To hear the interview in full with Dr Pahan, visit our Soundcloud here:

Scan me

Real Life Stories

Real Life Stories
Sumon's Journey

Sumon is 39 years old and lives with his wife and one year old daughter in a village called Hamayatpur Boatgor in the Pabna District, Bangladesh.

Sumon first noticed symptoms of leprosy around 22 years ago and visited his village doctor on numerous occasions. He spent over 30000 Takas (£370), but because the village doctor was not trained in spotting the signs of leprosy, Sumon was not given **multi-drug therapy** (MDT) or suitable follow-up care which could have prevented his condition from worsening.

In 2006, Sumon's friend, a rickshaw driver who had himself been successfully treated for leprosy, noticed his deteriorating condition and suggested he visited the Pabna Sadar Health Centre. Sumon took the advice of his friend. Lepra specialists examined him and diagnosed leprosy. Because of a lack of early treatment, Sumon was suffering with **significant injuries** to his feet. Lepra immediately referred him to Nilfamary Hospital where he was admitted for extensive operations, 6 months of post-operative care and multi-drug therapy to treat and **cure him of leprosy**.

Sumon's disabilities however, left him unable to continue his employment as a farm worker. He was left with **no income** and was struggling to feed his family. As part of his care package, he was referred to a local **SSG**, where he was given financial assistance to help him fulfil a dream of starting his own business. In the spring of 2014, Sumon opened his first grocery shop, which soon gave him over **150** customers a day.

He also started producing his own food products, such as **Chanachoor** (a savoury snack) which has proven to be very popular and is in great demand. He supplies around 600kg of Chanachoor per day, earning the business around **£600** each day.

This has enabled Sumon to grow his business and he now **employs 15 people**, including several who also have disabilities as a result of leprosy. As the business is growing, Sumon is expanding his operation and is investing in livestock and more outlets. A priority is to continue to **offer employment** to more people who have been affected by leprosy.

With the help of Lepra, Sumon has taken a leading role in the development of a new district federation in Pabna, so he can help others in the way he was helped by his local SSG. The federation now represents **111 SSG's** with over **1,433 people** attending the groups regularly. As secretary of the federation, Sumon is currently working with **local government** to have the federation formally recognised with the Department of Social Welfare, which he anticipates will be completed soon.

Sumon's journey demonstrates both the continued need for **early case detection** but also the power of providing people affected by leprosy and lymphatic filariasis with the support and infrastructure to find their own voice, to take ownership of their own care and the confidence to **follow their dream**.

Drink tea, eat cake and **change lives.**

Celebrate and support people affected by leprosy by hosting a life-changing tea!

What better excuse to get together with your friends for an afternoon of tea, cake and fundraising? Whether you're celebrating a birthday, an anniversary or having a street party for the Platinum Jubilee!

Your fundraising event is as easy as 1, 2... Tea!

Making a success of your life-changing tea **couldn't be easier**! All you have to do is keep the tea flowing, ensure you have lots of tasty treats, and simply ask for a **donation from your guests in return**.

You will have a **great time** and the icing on the cake, is that the funds you raise will help vulnerable people in India and Bangladesh, access leprosy treatment easily.

Visit our fundraising page to see our **top-tips** on running your own Lepra event and remember to send us your **amazing pictures** and let us know how you got on!

Scan me

Watch this Gallery Space!

Documentary photographer Tom Bradley's thought provoking series of portraits and real life stories, showing an alternative view of people affected, in the 'New Faces of Leprosy' exhibition.

In 2019 Lepra Trustee and Emeritus professor Diana Lockwood travelled to India with Tom Bradley, professional photographer, to document the lives of those people affected by leprosy.

These stories showcase that often, when receiving their diagnosis, many people felt despondent, depressed and in some cases even suicidal. It was clear their mental health suffered and they did not wish to share their diagnosis. However, after treatment they had positive messages about the curative nature of multi drug therapy and the support of staff and other patients at the health centres.

It became clear, listening to people's stories that for women in particular, they fear for not only their own position, but for their daughters too, including the potential challenges of a arranging a successful marriage.

Following an unexpected, pandemic related hiatus, we are thrilled to announce that the New Faces of Leprosy exhibition will be **touring again** this Autumn. We will be announcing venues shortly so stay tuned for further updates on the Lepra website or sign up for our monthly **e-newsletter**.

The Warmest of Welcomes

It was our pleasure to join the Ladies Group of the URC Christ Church, Colchester in April.

The group have supported Lepra for nearly 30 years, an incredible commitment from some truly **wonderful people**!

Since the pandemic, most of our talks are now held virtually, but during a recent visit to Lepra's HQ in Colchester, **Mowmita** and **Maria**, Programme Managers for India and Bangladesh respectively, stopped by to visit the ladies group.

Mowmita and Maria gave the group an update on the projects which are delivered in India and Bangladesh, followed by a **lively discussion** and some great questions from the ladies. In particular, Lepra's evolving approach to healthcare and how we faced and overcame the **challenges of the pandemic**.

If you would like to book a virtual presentation for your church, community group or school, please do get in touch with us to **discuss the options**. Please contact: AbiW@lepra.org.uk

Celebrating 70 Years
The Platinum Jubilee

Lepra's volunteer researcher, **Jane Hadcock** looks back at Her Majesty's incredible **70 years** of commitment to Lepra

Lepra is proud to have Her Majesty The Queen as patron and The Duke of Gloucester as vice president.

Lepra's relationship with the Royal Family commenced in **1924**, when the Prince of Wales, the future King Edward VIII became patron of the British Empire Leprosy Relief Association (BELRA), now known as Lepra. Her Majesty The Queen has been Lepra's patron since **1952**.

Lepra's Royal patronage has performed a **vital role** in helping us keep leprosy in the public's collective consciousness. Our close relationship has enabled us to remind the world that leprosy **still exists** and importantly, with treatment is **curable**.

Her Majesty The Queen's **deep empathy** for people affected by leprosy, as demonstrated throughout numerous visits to our programmes, centres and fundraising events, has played a key role in breaking down the barriers of prejudice and discrimination, leading to a **cultural shift** in the perception of leprosy, and greater care and empathy for the people which it affects.

Her Majesty The Queen, had taken an interest in leprosy as early as **1947** when she was one of the first Royal sponsors of BELRA's **Child Adoption Scheme**. The scheme was used to house, educate, feed and treat children with leprosy.

Her Majesty sponsored two children at the Itu Leprosy Settlement in Nigeria, one of them a young girl called **Budesta Kevina**. With this support, Budesta received treatment, an education and the chance to flourish.

Following her wedding in November 1947, Princess Elizabeth sent a portion of her wedding cake to the Girl Guides at Itu, which became affectionately known as '**The Nigerian Slice**'.

Her Majesty later provided support to build a new home for children where the adoption scheme was being introduced in Tanganyika (now Tanzania). She continued to **sponsor children** in Africa and India.

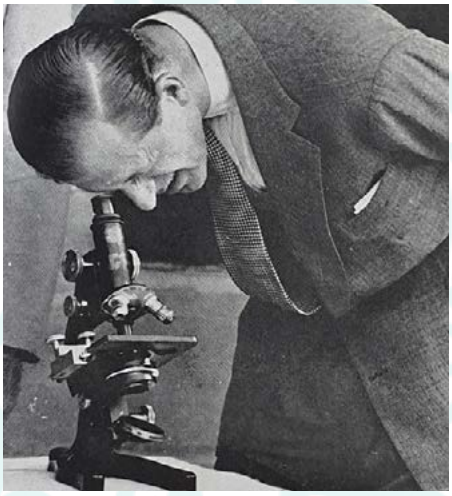
The Royal tour of South Africa in 1952 had an enormous impact because the then Princess Elizabeth and Princess Margaret, notably came away from the royal party to speak with a group of children who were only able to watch in "sad isolation". In such small ways, do **big changes start to happen**.

Prince Philip was also been a long-standing supporter of Lepra.

In **1956**, during the Royal visit to Africa and as a part of their support of Lepra, Her Majesty and His Royal Highness met with many people affected by leprosy.

Prince Philip was notably warm, sympathetic and supportive of all those he met with leprosy. These included a young boy he kindly sponsored. During one visit to Lepra's programmes in Africa, His Royal Highness took a **particular interest** in the scientific advances following Lepra's pioneering use of **Dapsone** as the first cure for leprosy.

Accompanied by **Dr Davey**, His Royal Highness was famously photographed peering into a Lepra microscope at the leprosy bacilli. Dr Davey was able to answer the Duke's many questions.



As we look forward to the **Jubilee**, we also keep a close eye on another international event this spring. The **Commonwealth Heads of Government Meeting** 2022 will take place during the week of 20 June 2022, in Kigali, Rwanda.

The theme for this year's Commonwealth meeting is: Delivering a Common Future: Connecting, Innovating, Transforming. With Lepra's progressive approach to healthcare in two prominent Commonwealth counties, we feel well placed to meet the challenges that the coming years are sure to present.

We hope you all have an amazing Jubilee and a sincere thank you to you, our wonderful supporters, our ambassadors, trustees and staff who continue to champion the rights and health of the **world's most vulnerable people.**

A special thank you to Her Majesty the Queen and the Duke of Gloucester.

Become a Monthly Life changer

By supporting Lepra with a **regular gift** you are helping us to reach some of the most vulnerable people in India and Bangladesh, people affected by leprosy. People like **Anasuya**, who suffered severely with her mental health after years of hiding her symptoms and disabilities due to leprosy.

Anasuya received treatment and **reconstructive surgery** which has transformed her life. Now healthy and happy, Anasuya says that her son is the 'most important thing in her life'. Read her full story here: **www.lepra.org.uk/real-life-stories/detail/anasuya**

Turning your donation into a **monthly gift** can impact even more lives, just some examples of the difference your kindness can have.

- **£3 a month will buy 12 vital self-care kits, including gauze, cotton wool, soap and Vaseline**
- **£6 a month could help support a child undergoing leprosy stay in school**
- **£12 a month could help two people disabled by leprosy keep their independence by providing wheelchairs**
- **£24 a month could provide 11 clinics with vital soaking and dressing materials for a year**
- **£30 a month could pay for a person with disabilities caused by leprosy to receive life changing reconstructive surgery**

Our monthly life changers are a **vital part** of our work to beat leprosy. Find out below why regular giving is so important, and beneficial to you too.

- **Changing Lives** - You will be helping people and their families affected by leprosy and LF receive the right care, at the right time and in the right place
- **Sustainability** – Monthly giving means we can plan future projects in the areas which need it most
- **Convenience** – A regular gift is easy to set up and spreads your giving across the year
- **Keeps costs down** – Regular giving helps keep our administration costs down and reduces fees for processing bank card fees and other payments, meaning even more of your donation can go directly to the people who need it most
- **Impact** – You will receive regular updates and insights into the impact you are having to change lives

Become a monthly life changer and have 12 times the impact today!

Scan me

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**

Registered with FUNDRAISING REGULATOR
Member Organisation Chartered Institute of Fundraising

Lepra, 28 Middleborough, Colchester, Essex, CO1 1TG
01206 216 700 - www.lepra.org.uk - lepra@lepra.org.uk
Registered charity number: 00213251 (England and Wales) SCO39715 (Scotland)

lepra
We will beat leprosy together