

LEPROSY VIEW

A collaborative newsletter brought to you by Lepra and the Rotary Clubs of Delhi South, New Delhi, Delhi Southend, and Regency Next.

Welcome

to the first edition of Leprosy View. Here you will find all the latest news and highlights from our collaborative life-changing work.

Our story began in October 2019, when Lepra and the Rotary Clubs of Delhi South, New Delhi, and Delhi Southend signed a partnership agreement to end leprosy in India. Our project aims to raise awareness of leprosy and significantly strengthen Active Case Finding and disability support in Delhi and beyond.



Suzanne McCarthy,
Chair of Trustees,
Lepra UK



Deepak Kapur, Rotary
Club of South Delhi



Members of Rotary and Lepra come together to sign the Memorandum of Understanding.

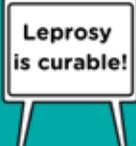
Leprosy is curable! Our partnership goal is to control leprosy in India, by creating a leprosy awareness and case detection campaign.

Year 1
Key targets

 **200,000**
people examined for leprosy in West Delhi.

  **228**
medical and health professionals trained

 **1,188**
health education campaigns

 **228**
school and college campaigns

 **1,188**
individuals reporting better quality of health care services

At least **600** people are diagnosed each day; **50 of these are children**

Why? Because of **fear and lack of knowledge**.

Many believe that leprosy is a thing of the past, but the truth is, leprosy never went away! Last year, **214,000** people 'officially' contracted leprosy. **63%** of those reported, or **150,000** people, are from India. However, this figure is a significant **under-estimate** as many people who contract leprosy **fear** reporting it. Some prefer to seek private healthcare where their **anonymity** can be more easily guaranteed. For those who cannot afford private healthcare, the **vast majority**, they may choose to ignore it, resulting in **life limiting disabilities**.

There are over **3 million people** across the world living with undiagnosed leprosy. Every day the disease causes further damage to their wellbeing, health, livelihoods and futures.

In endemic countries, leprosy awareness is poor, diagnostic capabilities are under-represented, and treatment options are not widely known. The **taboos and myths** around the disease exacerbate the situation, making the plight of leprosy patients deplorable.

Ignorance about leprosy has been the biggest challenge in reducing this disease to insignificant levels.

The truth is that leprosy is a **mildly infectious disease, Multi-drug Therapy, the cure, is freely available**, and there is no risk of transmission once treatment has begun.

About Lepra

Lepra is a UK-based secular international charity working to beat leprosy. Lepra's patron is Her Royal Highness Queen Elizabeth II and Lepra's Vice President is His Royal Highness the Duke of Gloucester.

Lepra is evidence-led and works directly with communities in India, Bangladesh, and Zimbabwe to find, diagnose and support people affected by leprosy.

In India, Lepra has worked with people affected by leprosy since 1924 and today supports activities through its Indian registered affiliate LEPRO Society.

Lepra works by raising awareness, organising early detection and treatment, reducing prejudice and supporting people to transform their lives.

Last year, Lepra reached 41,506 people with leprosy through diagnosis, treatment and support, and reached 995,659 people through health education and awareness raising to reduce prejudice.

"We are profoundly grateful to Rotary for their hard work, dedication and support of Lepra. The partnership between Rotary International and Lepra will enable us to make a substantive difference to the lives of thousands."

- Rtn Nayan Patel, Lepra Trustee

Rotary and leprosy

The Rotary clubs of Delhi South, New Delhi, Delhi Southend and Regency Next have agreed on a mutual mission to control leprosy throughout India.

A group of four friends founded the world's first service club in Chicago on 23 February 1905. This was a humble beginning of an International service organisation called "Rotary".

Rotary aims to bring together business and professional leaders in order to provide humanitarian service and to advance goodwill and peace around the world.

Our forte is providing service to others, to promote integrity, and advance world understanding, goodwill, and peace through its fellowship of businesses, professionals, and community leaders.

Disease control has been a core mandate for Rotary International since the organisation's beginning.

Rotary has been working to eradicate polio for more than 30 years. As a founding partner of the Global Polio Eradication Initiative, Rotary has reduced polio cases by 99.9 percent since the first project in 1979.

*Our vision is to **control leprosy** throughout India*

Last year, with the Rotary Club of Delhi South in the lead, and together with the Rotary Clubs of Delhi South End, New Delhi and Regency Next, we formed an alliance with Lepra UK with the objective of developing a robust programme to address the **identification and support of leprosy** in India.

Initially, these activities will be focused on the Delhi NCR area and based on our experience, a focused programme will be developed to address the rest of India with the support of the wide network of Rotary Clubs in India, which we will actively involve to provide support based on the detailed guidelines and procedures developed together with Lepra in the Delhi Region. Rotary in India has the **network, the ability and the enthusiasm** to develop and execute a programme of this scale.

We envisage a ten-year project, to:

- create popular public awareness about how to identify the early symptoms of the disease, among the general public, health professionals and decision-makers.
- find all new cases, through health staff training and enhanced active case finding.
- reduce disability, with the provision of timely, appropriate support and services.



What is leprosy?

Leprosy is a mildly infectious disease caused by *Mycobacterium leprae*. The bacteria affect the skin, peripheral nerves, and the eyes.

Leprosy is curable, but if left untreated it can cause severe disabilities and blindness.

The transmission of leprosy is still not entirely clear, though it is widely thought to be passed on by breathing in infected respiratory droplets.

If leprosy is recognised in its early stages, it can be treated easily and it will not cause any disabilities.

Many of the social problems associated with leprosy could also be avoided if people were treated as early as possible.

Early signs of leprosy are usually discoloured skin patches, weakness of the hands/feet, loss of sensitivity of the fingers or toes and difficulty walking or lifting things.

Leprosy is entirely curable, thanks to a combination of antibiotics, known as multidrug therapy (MDT). The Government of India provides MDT free of charge to all who need it in India.

In 1945, Lepra was the first organisation to find a cure for leprosy. Currently, Rifampicin, Dapsone, and Clofazimine are used in combination with each other to cure a person of leprosy.

50% of people diagnosed with leprosy go on to suffer from severe depression and anxiety due to the trauma they have faced. The ripple effect of this is enormous.

This needs to change.

MDT is **free and available** from all Government Health Facilities



What do Rotary and Lepra seek to achieve?

To control leprosy in India; **the leprosy capital of the world.**

How Rotary will help.

We want to control leprosy in India through :

- Advocacy
- Social Mobilisation
- Creating a committed and trained health worker force - both Government and private
- Active Case Finding
- Disability support for those affected.

Any money Rotary invests in the initiative will be towards advancing any/all of the aforesaid objectives.



One of the first signs of leprosy are usually discoloured skin patches with sensory loss.

Why are existing health workers unable to achieve what Rotary hopes to achieve?

Rotary proposes to play the role of a catalyst by focussing attention on Leprosy.

The work of Active Case Finding will be performed by Lepra in cooperation with Government Health Workers (ASHA workers, ANMs, Anganwadi workers).

Through training sessions and small incentives (such as awards and recognitions) Rotary will motivate and galvanise health workers to pay more attention to leprosy. Health workers are charged with creating awareness and reporting suspected cases for dozens of diseases.

Rotary will create awareness among the community about the signs and symptoms of leprosy, and address fears and prejudices that lead those suffering to hide their symptoms.

Rotary will encourage private and Government health centres and practitioners to report suspected cases to a centralised centre.



Weakness in hands and difficulties holding things are symptoms of leprosy.

Why will Lepra and Rotary make a difference?

Rotary is able to create awareness and social mobilisation to a great scale, and we have an abundance of volunteers who will passionately pursue the cause; the voluntary work force is represented by 156,000 Rotarians, their families, friends, Interact and Rotaract, which is unparalleled.

Lepra has almost 100 years of experience diagnosing, treating and supporting people with leprosy. They have worked in India since 1924, and **pioneered the first ever cure for leprosy.**

Rotary is in a unique position to leverage off strong relationships with political leaders, bureaucrats, religious leaders and Indian corporate houses. Rotary's inherent strength is the fact that individual Rotarians live and work in India – hence, the business contacts, extended family members and circles of friends can open doors that may be closed for Lepra.

Why distribute free food to leprosy settlements?

The current initiative is to take care of an emergency situation created by the COVID-19 pandemic, where even self-employed traders/merchants/small manufacturers are facing an economic crisis.

The most marginalised sectors such as migrants and those affected with leprosy are facing a food shortage. The whole world (including Rotary International) is taking emergency measures to help the most marginalised sections of society fulfil their physiological needs (“roti”, “kapda” and “makan”).



Rotary Clubs of Bangalore West, Delhi South and Regency Next deliver vital food aid to leprosy settlements.

No one knows how many and what kind of meals a day the people living in the leprosy settlements were getting before the pandemic.

The free food initiative has a finite timeline. Hence, there is a crying need to catalyse the development of a vocational training centre/programme to enable those who survive through begging to earn a living and sustain themselves.

The Rotary Initiative plans to set up vocational training centres in leprosy settlements, beginning with a pilot programme. The skills taught would help people living in the settlements to produce articles which could be sold to organisations with which Rotarians are connected, following a “cooperative” model.