

## PRESS RELEASE

### **When is elimination not elimination?**

#### **When it is leprosy**

**St Francis Leprosy Guild, London, UK, 14 April 2022:** the elimination of a disease is usually considered a good thing. When fewer than one person in 10,000 has leprosy, the disease is declared eliminated, or no longer a public health problem.

According to its [Leprosy Control Program](#), Nepal has sustained the elimination of leprosy as a public health problem at the national level since 2010. But this major success story concealed a frightening truth. In 21 districts out of 77, leprosy was not eliminated at all. For example, in Gandaki Province, Pokhara, where SFLG's partner, Green Pastures Hospital is located.



**Gandaki Province, Pokhara, by kind permission of Tom Bradley**



**Long queues for treatment outside Green Pastures Hospital, by kind permission of Tom Bradley**

When the elimination of leprosy was declared in 2010, government health services were scaled back with terrible results for people with the disease. The provision of healthcare for leprosy or leprosy-related disabilities such as ulcers was reduced and the knowledge and ability to diagnose leprosy declined.

Now for every thousand people in Nepal, there are eight who live with leprosy. People are living with lifelong disabilities, ulcers that won't heal or, they become subject to the stigma and discrimination caused by leprosy. This figure is two and a half times higher than the global average.

“When elimination was declared in 2010, our NGO partners and donors withdrew their interest and their funding,” said Dr Ramesh Sharma, Dermatology Consultant, at Green Pastures Hospital. “Today our hospital is packed full of people needing treatment for leprosy.”

According to Dr. Sharma, even experienced healthcare professionals struggle to diagnose leprosy in its early stages, when the disease can be readily confused with scabies, psoriasis, or other skin disorders.



“Even dermatologists can misdiagnose leprosy and the younger doctors have never been exposed to leprosy, said Dr. Sharma. “Who is going to suspect a disease that has been declared eliminated?”

**Dr. Ramesh Sharma, Dermatology Consultant, by kind permission of the International Nepal Fellowship**

If leprosy is allowed to develop unchecked and untreated, it can be spread, unknowingly into communities and cause life-changing disabilities. It is estimated that four million people are undetected or affected by leprosy worldwide.



My greatest fear is that people with leprosy who are undiagnosed and untreated will spread the disease to others in their community or go on to develop terrible disabilities” said SFLG’s Chief Executive Officer, Clare McIntosh.

**SFLG’s Chief Executive Officer, Clare McIntosh. Copyright St Francis Leprosy Guild**

“Historically, when the term leprosy elimination has been used at a national, regional or global level, it hides the fact that leprosy still exists, undiagnosed, at a local level, in hidden, endemic pockets” she explained.

“I urge any government to think long and hard before declaring that any disease no longer exists at a general or statistical level. Our experience with leprosy shows that it can hide, undiagnosed without symptoms for years before slowly re-emerging with disastrous

consequences. We must think carefully by what we really mean by elimination in relation to leprosy. Otherwise, leprosy will continue to destroy lives" she cautioned.

Ujeli is 65 years old. She caught leprosy many years ago and by the time she was diagnosed, her hands were severely disabled by leprosy. Eventually her right hand was so badly affected by leprosy, it was amputated. She has lost fingers on her left hand and her her toes due to the damage caused by leprosy ulcers. She is totally dependent on her family for her survival, and she fears that they will eventually abandon her.

Ujeli's is a true story. This is what happens when leprosy is not diagnosed and not treated soon enough. There is no happy ending.



Ujeli, a patient at Green Pastures Hospital, by kind permission of Tom Bradley

**Green Pastures Hospital, Pokhara**

Green Pastures Hospital treats and rehabilitates patients affected by leprosy by providing Multidrug Therapy, surgery, counselling by former patients, self-care training for patients to prevent leprosy ulcers and impairments from developing and assistive devices such as wheelchairs and prosthetic limbs. The hospital treats around 25,000 people every year and there is no charge for people with leprosy.

**Nepal and leprosy**

Nepal is one of the poorest countries in the world. But its landlocked position, unemployment rate, lack of safe water and poor infrastructure are not its only challenges. Leprosy is greatly feared. Leprosy is a contagious, chronic, neglected tropical disease. If left untreated, it will progress and cause life-changing disabilities: blindness, ulcers and the loss of limbs. It can also spread to others. Leprosy was declared eliminated in Nepal back in 2010. That declaration led to serious consequences for people with leprosy. Healthcare for the treatment of leprosy or leprosy-related disability was scaled-back and the knowledge and ability to diagnose leprosy began to decline. Nepal is a WHO global priority country for leprosy.

For more information, please visit <https://www.stfrancisleprosy.org/>

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## **About SFLG**

St Francis Leprosy Guild (SFLG) is a UK-based, Catholic charity that is working towards a - leprosy-free world. We support the work of over 40 leprosy centres, clinics, hospitals, care homes and leprosy-related projects. We work in 13 countries worldwide in Africa, Asia and South America where leprosy is endemic.

## **About leprosy**

### **1. What is leprosy?**

Leprosy (also known as Hansen's disease) is a complex, chronic neglected tropical disease caused by the *Mycobacterium leprae* bacterium. It affects the skin, the upper respiratory tract and peripheral nerves in the hands and feet, and the eyes. Leprosy can affect anyone, at any age, but it is linked to poverty, malnutrition, and genetic susceptibility.

Leprosy remains a health problem in low and middle-income countries worldwide.

### **2. How is leprosy transmitted?**

It is thought that leprosy is transmitted via droplets from the nose combined with prolonged, close contact with infected individuals.

### **3. How is leprosy diagnosed?**

Leprosy is difficult to diagnose at its early stages, but it often presents as numb patches on the skin. Currently, the most reliable method to diagnose leprosy, is a slit-skin-smear test in the laboratory.

Leprosy may incubate for up to twenty years before presenting with any signs. If leprosy remains undiagnosed, the person affected may unwillingly transmit the disease throughout a community. However, within a short period of receiving multidrug therapy, a person affected by leprosy will no longer be infectious. If leprosy is diagnosed in its early stages, it can be treated readily, and it will not cause disabilities. Preventing disabilities from developing means people with leprosy are less likely to suffer from the stigma and discrimination that can destroy their livelihoods and entire lives.

### **4. How infectious is leprosy?**

95% of most populations have a natural immunity to leprosy. The remaining 5% become vulnerable, mainly through poor nutrition, poor living conditions, lack of hygiene and a weakened immune system. Leprosy is not hereditary.

### **5. Why are people with leprosy often so disfigured?**

People with leprosy lose all feeling in the affected areas and as a result, there is diminished awareness of harm from trauma or heat. Without treatment, the lack of sensation can lead to permanent damage to skin, nerves, limbs, and eyes. It can also lead to the development of reoccurring, lifelong, hard-to-treat ulcers.

### **6. Is there a cure? How is leprosy treated?**

Leprosy can be cured using multidrug therapy (MDT), available at no cost to patients from the World Health Organization. If MDT is taken in the early stages of the disease, permanent damage to nerves is completely avoided.

### **7. How many are affected by leprosy in the world today?**

In recent years, WHO statistics reveal that around 200,000 people are newly diagnosed with leprosy. The COVID-19 pandemic has had a significant impact on health services and leprosy programmes have been affected with a wide disruption to services in many countries. Of great concern is that people with leprosy may receive a late diagnosis and develop lifechanging, visible disabilities as a result. The 2022 WHO WER may reveal the hidden truth.

These statistics do not account for those people who have leprosy with no symptoms or, who are not diagnosed and are unwittingly transmitting it to their communities. In addition, the statistics do not include those individuals who have been treated for leprosy, but whose disabilities, caused by leprosy need ongoing healthcare needs, or those who are subject to leprosy stigma and discrimination.

### **8. Which countries have leprosy, where is leprosy endemic?**

\*The WHO has identified 23 global priority countries for leprosy, where over 95% of the global total of people detected with leprosy are found. The 23 countries are: Angola, Bangladesh, Brazil, Comoros, Cote Ivoire, DR Congo, Egypt, Ethiopia, India, Indonesia, Kiribati, Madagascar, Micronesia, Mozambique, Myanmar, Nepal, Nigeria, Philippines, South Sudan, Sri Lanka, Sudan, Somalia and Tanzania.

\*WHO Weekly epidemiological record, Global Leprosy Update 10 September 2021, 36, 2021, 96, 421-444 <http://www.who.int/wer>