

Accelerating the fight against leprosy

 **SFLG** ST FRANCIS LEPROSY GUILD



ANNUAL REVIEW OF 2021 PUBLISHED JUNE 2022



Michael Forbes Smith

† SFLG ST FRANCIS LEPROSY GUILD

A message from the Chair

I was delighted that, in October 2021, we were finally able to come together at our Annual Mass to celebrate St Francis Leprosy Guild's 125th Anniversary. It was wonderful to welcome all those who attended, and we were very grateful for all the kind donations sent in support of our work. I would also like to thank The Leprosy Mission for their excellent presentation on our joint Active Case-Finding project, which is being run by The Leprosy Mission Nepal and Anandaban Hospital Team. We are helping to train 30 community health volunteers to find hidden cases of leprosy in the high-risk area of Nepal's Province 2, where almost half of the country's new cases of leprosy are detected.

Due to the UK's highly successful Covid-19 vaccination programme, life is returning to normal here and we are now learning to live with the virus. Unfortunately, many countries where we work are still firmly in the grip of the

pandemic and I am grateful to all our supporters for continuing to remember the world's most disadvantaged. Your generosity means we were able to double our support for leprosy centres in 2021, including providing emergency relief to meet the needs of the most vulnerable.

With your support, we are also working with even more centres over the coming year, including Mutemwa in Zimbabwe, Jimma Leprosy Association in Ethiopia and Alert India in Mumbai. The wider we can cast



Patients of Jimma Leprosy Association in Ethiopia.

our net, the faster we can accelerate towards our goal of zero leprosy.

Around a quarter of the money the Guild spent in 2021 was invested in Active Case-Finding and we intend to grow this work in the year ahead. To prevent the spread of leprosy and reduce the number of people suffering disabilities, it is vital that the disease is diagnosed and treated as quickly as possible. Active Case-Finding in communities is a vital method of achieving this goal.

I'm also pleased to report that more of our centres are now involved in contact tracing and are administering doses of a medication known as LPEP to the immediate and wider contacts of leprosy patients. This intervention disrupts the transmission of leprosy for up to two years, stopping it from spreading from one person to another.



Through our TRACE operating strategy, examples of which you can read about in this Annual Review, we continue to expand the expertise, tools and treatments we have at our disposal to end leprosy once and for all. **Thank you so much for the part you play in this important work.**



This year, our Annual Assembly and Reception will be held at 7pm on Friday 4th November, preceded by our Annual Benefactors Mass at 6pm. Bishop Richard Moss of Arundel is Chief Celebrant and both events will be held at the Catholic Church of the Immaculate Conception, Farm Street Church, 114 Mount Street, London W1K 3AH.

I extend a very warm invitation to all those supporters who would like to attend either event, and once again to express my heartfelt gratitude for all that you do to support the Guild's work.



An end to leprosy is tantalisingly close

It is not often that we have the chance to radically change history, but the call to help people with leprosy gives us a very real opportunity to do precisely that.

Leprosy is the most terrible disease. I recently had the chance to meet people affected by it at our centres in Uganda. Some could no longer see. One person's face was visibly paralysed. Countless others had lost both their hands and feet and I also met a young boy who was so weakened, he could no longer walk.

These physical symptoms were only the beginning of their pain because they were also brutally ostracised from society, unable to help themselves and deprived of any help or sympathy from others.

An end to leprosy is tantalisingly close, possibly even within our lifetimes. In this Annual Review you can read how, in 2021, programmes you have supported stopped at least 3,828 people from suffering the severe disabilities we have seen in the past. Thanks to you they can go on with their lives - having jobs and families.



Clare McIntosh SFLG's Chief Executive Officer meeting patients.

On my recent visit to centres in Uganda, I was greeted by huge rounds of applause. When we spoke to individuals they said, ***“Everyone shuns us and looks the other way. No one offers us help. And yet we hear of you people, from many miles away, who feel our pain and help our suffering. We are so keen to know who you are.”***

Those people are you. Every day, you are making the difference.

As Chief Executive Officer of St Francis Leprosy Guild I feel enormously privileged in my role to represent you and to oversee this work being done. This year, you are enabling us to work with 40 leprosy centres spanning 13 countries.

St Francis Leprosy Guild is a relatively small charity but we can punch above our weight thanks to the partnerships we continue to



Patients and staff in Uganda are so grateful to our supporters.

forge, including those with Non-Governmental Organisations (NGOs) such as The Leprosy Mission and ILEP, a consortium of like-minded organisations that share a desire to see an end to leprosy. We are also working with the Leprosy Research Initiative on two innovative research projects that could help us achieve zero leprosy faster as well as improve leprosy care.

I would like to thank all our supporters and partners for the

valuable contribution you are making to the fight against this life-changing disease and I look forward to working with you in the year ahead. Together we will end leprosy once and for all.



Every two minutes another person is diagnosed with leprosy.

The past year in figures...

SFLG ST FRANCIS LEPROSY GUILD

These illustrations are just a few examples of what our supporters have helped us to achieve this year. The Guild would like to say a huge thank you for making them possible.

120,329

people have been screened for leprosy



We have helped to identify

3,828

people with leprosy



29,929

people have received direct treatment for leprosy



We have supported

37 leprosy centres



Our charitable expenditure totalled

£437,317



Our work spanned

13 countries



Archbishop John Wilson reflects on the urgent need to beat leprosy

The following is an edited extract from our 125th Anniversary Mass held at Southwark Cathedral on 30 October 2021, and led by Archbishop John Wilson.

“Perhaps, like me, you have heard people say that leprosy is no longer a problem; that a cure is available, as if there were no longer any issues to be faced. The truth, however, is more complex and makes the Guild’s work as necessary as ever.

Leprosy still occurs in more than 120 countries, notably in the poorest parts of the world, where there remain obstacles to affordable healthcare for those on the margins. Estimates indicate that someone is diagnosed with leprosy every two minutes,

that’s around 30 people per hour. Fifteen thousand cases in children are diagnosed every year, enough to fill over five hundred classrooms in an average British school. More than three million people live with disabilities caused by leprosy, and, unfortunately, there is still rejection and exclusion. Globally there are still 127 laws that allow discrimination because of the disease, while around four million people are thought to be living with undiagnosed leprosy.

Without the five-fold response of the Guild’s TRACE strategy, this situation is unlikely to improve and could get worse. And of course, Covid-19, with its own burden of suffering and isolation here and abroad, has made



addressing these needs all the more demanding. If we think leprosy is a thing of the past, then we are sadly mistaken. The Guild’s mission, working internationally in partnership, is to end leprosy for good. Until then we can each play a part in achieving this goal.

We give thanks for all that has been achieved. And we ask God to abundantly bless the work of St Francis Leprosy Guild in the years to come.”



15,000 children are diagnosed with leprosy every year

TRACE+

Our strategy to end leprosy

When the Guild joined the Global Partnership for Zero Leprosy in 2021, we devised our own strategy in support of its vision: **no disease, no disability, no discrimination, and no stigma. We call our operating strategy TRACE, which stands for Training, Research, Active Case-Finding, Care and Emergency Response.**

Training

We fund all types of training to help stamp out leprosy and improve outcomes for those with the disease. This ranges from equipping outreach workers and volunteers with the skills to diagnose and treat new incidences of leprosy, to supporting education and awareness raising activities in local communities. These initiatives enable and encourage people to self-refer at the very first sign of leprosy symptoms.

Research

Currently, we are an Associate Member of the Leprosy Research Initiative and also collaborate with The Leprosy Mission, investing in vital research that could improve leprosy treatments. We're also harnessing smartphone technology to support accurate diagnosis and monitoring in order to prevent the spread of the disease and achieve zero leprosy sooner.

Active Case-Finding

To end leprosy for good we must root it out wherever it exists. Through Active Case-Finding projects in communities, those people with symptoms can be identified and treated before disabilities occur, and their contacts can receive medication to stop the disease from spreading.

Care

We continue to build upon our 126-year legacy of providing care, compassion and practical support to those who suffer from severe disabilities and stigma. We fund everything from reconstructive surgery to education in self-care, assistive devices to vocational training, helping to restore people's dignity and independence.

Emergency Response

People with leprosy are among some of the poorest in the world and therefore hugely vulnerable to shocks, such as pandemics and natural disasters. When the world's most vulnerable need our support, we are determined to be there.

Training

Combatting the social and psychological impact of leprosy in Ethiopia

Kedouse Youseph, a social worker in Ethiopia, works with the Jimma Leprosy Association, which is run by The Daughters of Charity. Jimma is located in the Oromia Region, approximately 350km from Addis Ababa. A large percentage of its population is affected by leprosy, and many are living with permanent disabilities.

Kedouse is all too aware of the huge stigma attached to those with leprosy and their families. He has witnessed how they are often the butt of derogative nicknames and are marginalised by their local communities, even after their leprosy has been cured. Many affected families find their self-esteem is destroyed and they totally

withdraw from society, which frequently leads to their economic downfall. They rely on begging and handouts to survive.

The latest data show that people with leprosy are 7.5 times as likely as the general population to suffer from mental health problems. While medical treatment and aftercare for leprosy patients is understood and regularly practiced, very little work has been done in Ethiopia on the social and psychological impacts of leprosy. However, it is clear to Kedouse that many patients and families who are affected by the disease experience loneliness and depression, while children may drop out of school or get involved in illegal or destructive behaviour.



“Really, without the Guild’s support it would be very difficult for me to further my PhD studies.”

Kedouse Youseph

We are supporting Kedouse to complete a PhD at the University of South Africa (UNISA) where he is studying the experiences and challenges faced by leprosy patients and their family members. Kedouse’s ultimate aim is to produce a set of guidelines for social workers in order to help improve outcomes for families affected by leprosy in Jimma, and across Ethiopia.

Research

Funding vital leprosy research

St Francis Leprosy Guild continues to champion new research that could transform the diagnosis and treatment of leprosy across the globe. Currently, we are supporting three key projects:

Mobile contact tracing app to reduce the spread of leprosy

As an Associate Member of the Leprosy Research Initiative (LRI) we are sponsoring the development of a mobile phone app that will improve the accuracy of recording and monitoring leprosy patients’ contacts. Even after receiving doses of LPEP – medication proven to disrupt transmission of the disease – contacts need to be monitored for five years. Being able to trace and manage a patient’s history

using a hand-held device will be transformative in remote communities, where current paper-based methods can be unwieldy and inaccurate.

Multi-spectral screening to speed up diagnosis

Working with The Leprosy Mission, we’re helping to develop pioneering diagnostic tools such as multi-spectral screening to help diagnose leprosy quickly and accurately during outreach work. Armed with the technology to make an accurate diagnosis using a scanner on a smartphone, a health worker can ensure a person with leprosy is treated immediately and spared a lifetime of disability.



Protective boot to improve the treatment of ulcers

Leprosy causes nerve damage, making people’s hands, feet and limbs very susceptible to injury and ulceration. We’re supporting a study into the use of a protective ‘boot’, similar to those used in the UK while a broken bone is healing. The study will collect data to measure how effective the boot is in offering protection during healing as well as any potential complications that could arise. This study will help decide whether its widespread use could become an effective part of leprosy patients’ ulcer care.

Active

Preventing the spread of leprosy in Karachi

Marie Adelaide Leprosy Centre (MALC) in Karachi, Pakistan, is running one of six Active Case-Finding projects supported by the Guild and due to last between three to five years. The aim of this project is to reduce the spread of leprosy in Landhi Korangi and Maskan-e-Rahat, two regions of the city where the people are impoverished and the disease is endemic.



Leprosy Technicians from MALC field centres have been given refresher training courses to help them identify new leprosy incidences that need immediate treatment, and to trace people's contacts in order to prevent the spread of the disease.

Initially, two skin camps were held between September and November 2021. In order to encourage as many people as possible to attend, prominent banners displayed the dates and times of the skin camps, as well as outlining leprosy signs and symptoms. 300 flyers were also distributed to shops, mosques and people in the street.

Local people were offered free skin examinations and medicines for a range



of skin conditions. In total, 895 men, women and children were examined at the first two camps. MALC also made house-to-house visits, screening 1,251 contacts of known and suspected leprosy patients. Three people were confirmed to have leprosy and another 26 were presumed to have the disease, pending further laboratory tests.

MALC plans to run these skin camps every three months in order that no leprosy cases slip through the net. Through awareness-raising and early diagnosis and treatment, Active Case-Finding projects like this one are playing an important part in the 'final push' to rid the world of leprosy entirely.

Care

Caring for the impoverished and the outcast

Millions of people from impoverished communities, where there is little or no access to affordable healthcare, have caught leprosy in the past and are living with severe disabilities today. For generations, St Francis Leprosy Guild has been working with its partners around the world to provide for their care.

Take the case of Shivalingham, a Sri Lankan woman aged just 40 who has had both legs amputated due to leprosy.



Day-to-day, she is cared for by her elderly mother but Shivalingham also receives regular visits from Sister Lalitha, on behalf of a leprosy centre supported by the Guild and run by the Order of Franciscan Missionaries of Mary.

"I take them provisions and nutritional supplements," says Sister Lalitha. "When I first met them, their house was dilapidated, and the roof was falling in. Thanks to the generous support of St Francis Leprosy Guild, we have since replaced the ceiling, provided running water and a toilet."

Sister Lalitha visits around 22 people every month journeying by car, bus, or auto rickshaw, often travelling on



"Because of the love and concern of the Sisters, we feel we are not alone."

rough roads for hours on end. She visits people with leprosy as their friend so their neighbours don't suspect a link to leprosy, and the stigma and rejection, so often associated with this disease, can be avoided.

She says: *"I am very grateful that through the Guild I can provide some support for people with leprosy otherwise they would be left on their own to perish. Everyone I visit is very grateful for everything that I can bring... It's almost impossible for them to survive without support."*

Emergency

The Guild provides emergency funds for Covid-19 recovery

In May 2021, many countries around the world were still experiencing an incredible level of Covid-19 infection. By far the most vulnerable were those with leprosy, a fact summed up by Father Innaiah Govindu, Superintendent at St Anthony's Leprosy Rehabilitation Centre in Prakasam, Andhra Pradesh, India.



"I am so sorry to let you know about the Corona tsunami we are experiencing," he said. "The outbreak of the virus has spread everywhere and is causing enormous destruction to human lives."

"Our leprosy community residents, too, are affected with Covid-19. I have kept them under home quarantine and we are treating them as best we can, but when normal patients are struggling for a place in the hospitals, it's almost pointless to mention the plight of these vulnerable and neglected people with leprosy. Right now, we are in the grip of fear and danger and don't know what our destiny will be."

The Guild was receiving similar reports from many of its centres across the



globe. Countless people with leprosy were struggling to source enough food and medication, while leprosy programmes were falling behind, storing up problems for the future; undiagnosed and untreated cases would mean more people developing life-changing disabilities.

It is thanks to the generosity of our supporters that the Guild was able to respond to this emergency with a grant of £60,000 across all our centres. This support has helped to provide essential supplies for people with leprosy through the pandemic and to get essential leprosy programmes back up and running.



Today, up to four million people are living with visible impairments or deformities due to leprosy.



Gwen Sankey served as President of St Francis Leprosy Guild from 1993 to 2015. During this time her husband, John, saw an opportunity to support her in her work – partly to say ‘thank you’ for her tireless efforts throughout his diplomatic career in many countries. They had both become aware of the need for leprosy outreach, treatment, and rehabilitation when John was serving as British High Commissioner in Tanzania. Their frequent visits to distant parts of that large and fascinating country meant that they had personal connections to the leprosy centres there.

Gwen relied on John’s support and help in many of the Guild’s activities. A genial host, he and Gwen loved to welcome visiting leprosy specialists to their flat in central London. He used to be deeply involved in the compilation of the

Guild’s Annual Review, and his considerable diplomatic and Catholic connections were invaluable when helping to assess applications for our annual and project grants.

Possibly most important, and least known, was the work he did to ensure that complex legacies left to the Guild actually arrived. His willingness to tackle bureaucracy and disentangle complicated documents, honed through his decades as a diplomat, made him especially suited for this role.

One of his proudest moments is captured in the accompanying photograph, when Gwen was awarded the Papal medal ‘Bene Merenti’ for her years of work for the Guild as its President.

We offer our sincere condolences to Gwen and her family. John remained involved with the Guild until 2020 and is greatly missed by us all



These images show projects so generously funded by previous bequests.

Make or update your will for free with the help from the Guild

We’re delighted to announce that St Francis Leprosy Guild has partnered with Your Legacy Solutions, giving our supporters the opportunity to leave a bequest to the Guild by making or changing a will with the help of a specialist advisor. You can register your interest in using this free service by visiting **www.stfrancisleprosy.org/wills-and-legacies**

Most people’s estates are relatively straightforward and there will be no charge to make or update a simple will

for a single person or a mirror will for a couple. Should your will prove to be more complex, your advisor will let you know of any additional costs you may incur before you start the will-writing process and you can decide whether to proceed or not.

Leaving a gift in your will is a very special way to go on supporting the Guild’s work until the fight against leprosy is finally won. Gifts of any size are greatly appreciated and make a big difference to our future work.

If you would like to know more about how to leave a gift in your will and all the good it can do, please visit **www.stfrancisleprosy.org/wills-and-legacies** where you can download a copy of our legacy pack. Alternatively, please call **020 8050 4201** or visit **www.yourlegacysolutions.co.uk/SFLG** if you would like to talk to a specialist advisor, in confidence, about your plans.

‡SFLG ST FRANCIS LEPROSY GUILD

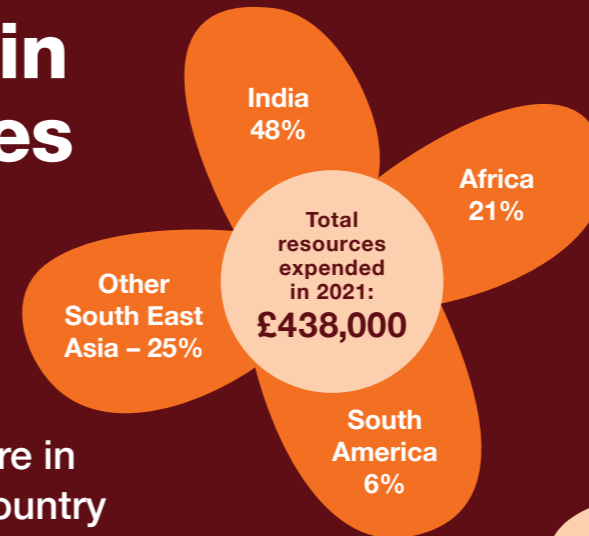
**In memory of
John Anthony
Sankey
PhD CMG**



98.5% of new leprosy cases are found in just 23 countries – a global priority for diagnosis and treatment.

The past year in figures

Expenditure in 2021 by country

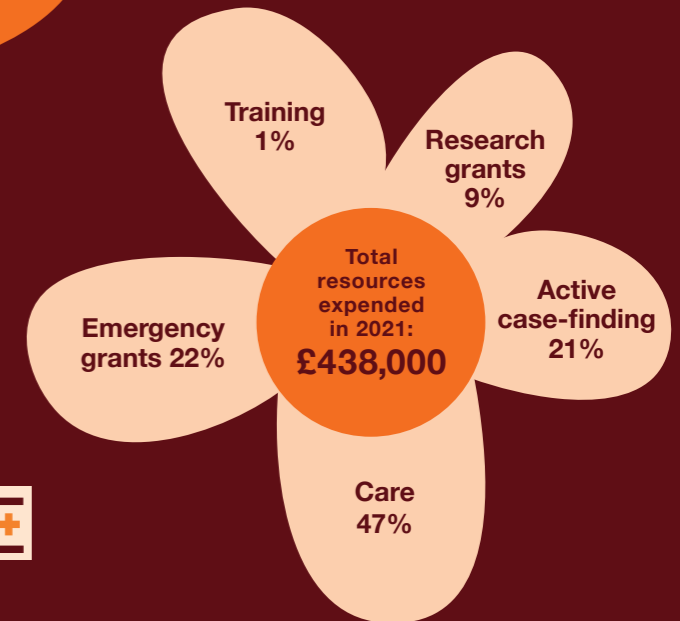


Expenditure in 2021 by



Full accounts are available from the website www.stfrancisleprosy.org/reports-and-publications

This illustrations show how we funded projects throughout the world for the year ending December 2021 and also how that income was used to provide grants to partner organisations across the world.





Tel: 0300 770 2856



enquiries@stfrancisleprosy.org



www.stfrancisleprosy.org

Follow us on:



St Francis Leprosy Guild, 73 St Charles Square, London W10 6EJ
UK Registered Charity No. 1188749

SFLG ST FRANCIS LEPROSY GUILD

Global Partnership for
Zero Leprosy

LEPROSY RESEARCH INITIATIVE

Registered with
**FUNDRAISING
REGULATOR**

Thanks to Tom Bradley for permission to use his photos of leprosy patients in Nepal.