



Bringing hope in the midst of crisis

SFLG ST FRANCIS LEPROSY GUILD

COVID19

SFLG ST FRANCIS LEPROSY GUILD
Compassion in Action, Sustaining Life & Hope

Response to COVID19

The provision of dry ration kit and safety precautions
to persons affected by leprosy in Maharashtra

#COVID19

ANNUAL REVIEW OF 2020,
PUBLISHED JUNE 2021



A message from the Chair of Trustees

Michael Forbes Smith

Over the past year, Covid-19 has plunged the world into crisis. Nevertheless, thanks to the unfailing generosity of our supporters, the Guild and its partners have continued to bring hope to people affected by leprosy.

Despite considerable logistical difficulties, the partner organisations that we support have done their utmost to continue caring for their patients and conduct their vital work, identifying and treating new leprosy cases. The Guild has also funded an emergency food project in India for people with leprosy who have had no means to feed themselves during the pandemic.

Even though members of the Guild have been obliged to work from home over the past 12 months, and Zoom calls have become our new temporary way of working, I'm pleased to say

that the charity has refused to stand still. I would like to welcome two new Trustees, Liam Allmark who has joined as the representative of the Catholic Bishops' Conference of England and Wales, and Cecilia Taylor-Camara who brings considerable experience of working in lower income countries. In November 2020, Clare McIntosh also joined as the Guild's new Chief Executive Officer, since when she has been raising awareness of our work and recruiting new supporters who are eager to join the fight against leprosy.

Last year, the World Health Organization (WHO) restated its determination to end this disabling disease, announcing its new goal: 'Towards zero leprosy'. I am determined that the Guild will continue to play its part and we have been refining our own strategy in support of the WHO mission. I am pleased to announce that, for the first time, we have become an Associate Member

of the Leprosy Research Initiative and have joined The Global Partnership for Zero Leprosy to help us make faster progress towards a leprosy-free world.

In 1995, WHO made multi-drug therapy freely available to nations where leprosy is prevalent. It became a game-changer. Since then, more than 16 million people have been cured of the disease. Today, the drug Rifampicin is bringing yet more hope of containing the spread of leprosy since it has proved to disrupt transmission when administered to leprosy patients' community contacts as a preventative measure. The Guild is excited to be working with the Leprosy Research Initiative to develop a new mobile phone contact-tracing app. This will support healthcare workers in the field so we can ensure that all contacts are identified and given preventative treatment **before the infection can take hold**.

As our supporters will know, we have been celebrating the 125th anniversary year of the Guild. Unfortunately, last year due to Covid-19, we were unable to kick off our anniversary with our planned inaugural celebration, but we very much look forward to concluding it with a celebratory Mass at St George's Cathedral, Southwark, in October. This will be presided over by Archbishop John Wilson and followed by a drinks reception. I would like to extend a very warm invitation to all those supporters who would like to attend.

As ever, my heartfelt thanks go out to everyone who is working with us to end leprosy. Together, we will help beat this life-changing disease, once and for all.

A handwritten signature in black ink, appearing to read "Michael F. Smith".



ST FRANCIS LEPROSY GUILD Annual Mass 2021

**Presided by
Archbishop John Wilson**

**St George's Cathedral,
Lambeth Road, London SE1 6HR**

on 30 October 2021 at 12.30pm

**Reception to follow at
Amigo Hall, Lambeth Rd,
South Bank, London SE1 7HY**

All are welcome

Leprosy: the facts

Leprosy - also known as Hansen's disease - is a chronic bacterial disease transmitted largely via droplets from the nose. Around 95% of us have a natural immunity to leprosy but the remaining 5% become vulnerable due to poor nutrition, poor living conditions, lack of hygiene and a weakened immune system. This means the disease is still endemic in parts of India, Asia, Africa and South America.



Sah Kendor. Massatine Centre. Photo©Tom Bradley

The first sign of the disease is often discoloured skin patches and sensations of numbness, burning or tingling in the hands and feet. People with leprosy may also find it difficult to lift or hold things, or to move or walk. If left untreated, the nerve damage that is responsible for loss of feeling in the hands and feet makes people more vulnerable to injury caused by trauma or heat. This can eventually lead to the loss of fingers, toes, limbs or eyesight.

Fortunately, there is now a cure for leprosy. Multi-drug therapy arrests the progress of the disease and stops the person from being contagious. This means, if caught early, permanent damage to the nerves can be avoided, preventing people from suffering severe disabilities that would otherwise have a lasting impact on their lives and livelihoods. Early treatment and detection can also stop the disease being passed on to others.

The Guild supports partner organisations that are involved in Active Case-Finding, in order that treatment can be given to patients before the disease takes hold and a preventative drug can be administered to their contacts in line with the new World Health Organization recommendations. Tracking, tracing and treating leprosy is the only way we will bring about zero leprosy.

The stigma of leprosy ruins lives

People frequently hide the early signs of leprosy for fear of being cast out by their community or discriminated against by local legislation. For example, until 2016 India still had 120 discriminatory laws affecting the rights and freedoms of people with leprosy. Today, 116 of these are yet to be repealed. This is why the Guild is working with its partners to educate people about leprosy and prevent people with the disease from being marginalised. Where stigma still exists, so will leprosy.

“I was cast out by my family”

Durga Soren once lived with his wife, two sons and a daughter in a house tied to his father's job on Indian Railways. Fifteen years ago he developed leprosy symptoms so Durga's wife and children threw him out to prevent the remainder of the family from losing their home. They feared that Durga was likely to be ostracised by the local community.

Durga survived by begging until state laws prohibited this during the pandemic. A staff member from Karunalaya Leprosy Care Centre, in Puri, found Durga in a terrible state, with unkempt hair and dirty bandages around



his hands and feet. He was also dehydrated and unable to walk.

The centre is supported by the Guild, and the food, care and leprosy medication they provided made an immediate difference to Durga's condition. As long as he completes his six-month treatment, Durga will be cured of the disease and can set about rebuilding his life.

The past year in figures...

These are just some of the things our supporters have helped us to achieve over the past year.
The Guild would like to say a huge thank you for making them possible.

223,099

people
have
been
helped



26,938

people have
received direct
treatment
for leprosy



Charitable
expenditure
totalled

£383,622



100,420

have been
screened
for leprosy



We have
supported
30
partner
organisations



Our work spanned
12
countries



T R A C E

Our strategy to end leprosy

In 2020, St Francis Leprosy Guild devised its own strategy, both to support the global goal of zero leprosy and to define the work that we will continue to support. We refer to our five-pronged approach as T.R.A.C.E. and this is what it stands for:

Training

The Guild helps to fund vital training of local health workers and volunteers who are rooting out leprosy in people's communities. We provide grants for UK medical students who wish to gain experience of working with leprosy patients, and we also support people affected by leprosy to learn vocational skills so that their dignity and independence may be restored.

Research

Working in partnership with the Leprosy Research Initiative, we are sponsoring vital research projects that can help to end leprosy for good. For example, there is still no vaccine for leprosy, nor any fast and effective diagnostic tests. We are helping to address issues like these.

Active Case-Finding

To beat leprosy, we need to know exactly where it is. The Guild supports outreach work in people's communities, which raises awareness of leprosy, monitors people for early symptoms, oversees treatment, and traces the contacts of those who test positive so we can stop the disease in its tracks.

Care

The Guild supports leprosy hospitals and clinics that provide comprehensive treatment and care, both to help cure leprosy and to minimise the complications that can stem from the disease.

Emergency Relief

People affected by leprosy are often physically and economically vulnerable. Covid-19 has highlighted, yet again, our need to support people with leprosy in the wake of emergencies such as a pandemic or natural disaster.

T

Training to spot early signs of leprosy Beating leprosy in the Amazon



Access to these communities is only possible by boat or air so Dr. Tony and her team have to use a hospital boat to travel from one community to another, in order to provide treatment for those who need it. There are 199 different communities along this stretch of the Amazon and their only access to healthcare is the hospital boat, without which they would have to travel to the town of Labrea, which takes several days.



Many of our supporters will already be aware of the work of Dr. Antonia Lopez Gonzalez (Dr. Tony) and the Ipiranga Committee Association. The doctor and her team of healthcare workers and volunteers care for people affected by leprosy in isolated communities on the Purus River, in the Amazon region of Brazil.



Dr. Tony examining a patient

Over the past two decades, the Ipiranga health initiative has been working to end leprosy in the region and Dr. Tony has recently been nominated for a prestigious award for her work. She has recruited and trained hundreds of local health workers who conduct house-to-house visits, carrying out skin examinations so they can spot and treat leprosy in its early stages. They also run health



education sessions with children and young people to make them aware of the first telltale signs of leprosy, and to help remove the stigma that still surrounds the disease.

Gael, one of Dr. Tony's patients, first noticed early symptoms of leprosy when he was just 10 years old, but

he hid them from his family for fear of being cast out by his community. Gael had pain in his arms and fingers and gradually found he couldn't move his little fingers at all because leprosy had caused severe nerve damage. He was terrified that his fingers would need to be amputated and that once people knew he had leprosy they would reject him.



Thanks to the arrival of the hospital boat, a member of Dr. Tony's team was able to diagnose leprosy and persuade Gael that, with the right

treatment, his hands would improve. He received multi-drug therapy and after several years of physiotherapy, he is able to use his hands again. Members of Gael's family and some of his other contacts have also been examined and found to have leprosy. Thankfully, they have not suffered disabilities because medication stopped the disease before it took hold.

With the help of the Guild and our supporters, the Ipiranga health initiative carried out more than 48,300 examinations of people living in the Purus region last year. Dr. Tony and her team also provided training in leprosy care and prevention for 480 healthcare assistants.

R

Research to aid accurate diagnosis A new research partnership



St Francis Leprosy Guild has begun its first ever collaboration with the Leprosy Research Initiative (LRI). We are helping to fund research into the development of a mobile app that, compared to current paper-based methods, will offer a more accurate way of recording and

monitoring leprosy patients' contacts. This will help to reduce transmission of the disease.

According to data from the World Health Organization, South East Asia reported 71% of global leprosy cases in 2018 and by far the largest proportion were in India. Having consulted with Indian health workers engaged in identifying and



monitoring leprosy cases, the LRI cites cumbersome, paper-based record keeping as one of their biggest stumbling blocks, especially when the work is being conducted in remote areas.



If the contacts of people who have tested positive for leprosy are given a single dose of the drug Rifampicin, it has been able to disrupt transmission of the disease. Since 2018 this practice has been adopted as part of India's National Leprosy Eradication Programme (NLEP)

but implementation has proved difficult. There have been major gaps in contact listing, screening and provision of the drug.

Using contact tracing apps on a smart phone has already proved successful in combatting the spread of other diseases, including Covid-19. Therefore, the Guild has contributed £60,000 towards this leprosy research programme, which will develop and evaluate a mobile app against current paper-based methods. The research will be conducted in a rural and urban district of West Bengal, where leprosy is still endemic and the NLEP highlighted an urgent need for more effective Active Case-Finding.



A

Active Case-Finding and Contact Management Restoring hope in Bangladesh



Supporting Dhanjuri Leprosy Centre

The Guild has been working with Dhanjuri Leprosy Centre for more than twenty years, yet there are still considerable physical and cultural barriers to overcome in their fight against leprosy.

There are a limited number of professional health workers in the region who are trained in leprosy detection and care, and many of the communities they need to visit are very remote. What's more, the people who live in them often prefer to consult with the village 'janguru' rather than attend a hospital or clinic.



Nevertheless, Dhanjuri Leprosy Centre is determined to beat leprosy in the district of Dinajpur and it

carries out a range of activities to help identify new cases and reduce transmission, including:

- Community education campaigns to help dispel the myths surrounding leprosy whilst enabling local people to spot early symptoms.
- Medical examinations in those schools and colleges where new leprosy cases are suspected.
- Contact tracing within families and the wider community.
- Training of more health workers and volunteers to conduct Active Case-Finding.

In the past year alone, the centre has identified 273 new leprosy cases, including 14 children, all of whom will now be receiving treatment.

Dhanjuri Leprosy Centre also provides care and rehabilitation for those patients who have already developed disabilities. This includes skills training and income-generating activities to help people regain their independence.

None of this would be possible without the generous donations we receive from the Guild's supporters. Together, we are beating leprosy, one community at a time. To watch a short video made by Dhanjuri Leprosy Centre, please visit our website at www.stfrancisleprosy.org/case-studies

Monjur Kha is a patient of the Dhanjuri Leprosy Centre in Bangladesh. He is 46 years old and first experienced leprosy symptoms two years ago.

His left foot began to feel numb and he was finding it harder to walk. Monjur needs to work in order to support his wife and daughter, so he was terrified of being disabled permanently because he knew their lives would be ruined.

Outreach workers from the Dhanjuri Leprosy Centre visit Monjur's village to educate local people in how to spot the early signs of leprosy. At one of these sessions, a healthcare assistant examined Monjur and was able to refer him for treatment. He began a six-month course of multi-drug therapy and day-by-day feeling was restored in his foot and he began to feel well again.

Monjur has also had advice on how to take care of his feet to avoid injury, and the centre has supplied him with protective footwear. He knows they are also there if he ever suffers any



complications in the future. His family and contacts have been examined for leprosy and, fortunately, there is no sign that they have the disease so Monjur is now able to concentrate on realising his ambitions.

Before Monjur had leprosy he was earning money as a labourer. Now he has his own tea stall but his dream is to run a hotel one day. Since he is now cured of leprosy there is no reason why, with hard work and determination, his dream shouldn't come true.

C

Caring for people with leprosy

Fighting stigma in Nigeria



The Ogoja region of Nigeria has very good healthcare provision. In fact, the diocese has four major hospitals in Ogoja, Ikom and Obudu, in addition to many community health centres. However, leprosy remains endemic here because the disease is still seen as a curse. Many of those

who are afflicted by leprosy hide their symptoms or continue to seek help from traditional healers. As a result, it is often too late to prevent them from suffering disabilities themselves and the disease will have already been transmitted to others.

Across the world, Covid-19 has made fighting leprosy much more difficult but St Benedict's Leprosy Rehabilitation Centre, in Ogoja, still carries out an impressive programme of care, rehabilitation and preventative work, as best it can.

The centre conducts examinations in local primary and secondary schools in order to diagnose the disease early and provide prompt treatment. That way, children can avoid developing

the kinds of complications that Cecilia (pictured right) suffered when she was just eight years old. St Benedict's is also engaged in Active Case-Finding to detect and treat new cases of leprosy as soon as they arise in the wider community.

Ongoing medical care is provided for those patients who may have developed complications after contracting the disease, while those people whose disabilities have caused them to lose their livelihoods receive a monthly food allowance. Young people who are able to work are also supported with vocational training, after which St Benedict's will assist them to set up in business so they can maintain their dignity and independence.

"Without this centre I would have died a long time ago."



Cecilia is now 79 years old. She was diagnosed with leprosy when she was eight. Her symptoms began with rashes on her arms and legs but as they grew worse and she developed wounds on her fingers and toes, she eventually had to have all of them amputated.

For the remainder of her life Cecilia has been receiving care at the Marian Rehabilitation hospital run by St Benedict's. In fact, she met and married her husband there and has had children who were supported through school by the centre. Cecilia's



Cecilia's feet being examined

children are now married too and live with their own families, free of the disease that their mother has been battling all her life.

With the help of the Guild's supporters, St Benedict's has been able to provide Cecilia with shelter, food, medicine, clothes, money and company. She says: "Without the support of this centre I would have died long ago because of hunger, illness or shame. I want people to know that leprosy is curable and that they should not reject people with the disease."

E

Emergency and relief projects

Covid-19 emergency food project



therefore reliant on others for their survival.

In 2020, after the pandemic struck, St Francis Leprosy Guild teamed up with Lepra to provide emergency food rations for people affected by leprosy living in the Indian state of Madhya Pradesh. Hundreds of dry rations and PPE supplies, including gloves and masks, were distributed with the support of St Joseph's Leprosy Centre, District Leprosy Officers and National Leprosy Eradication Programme (NLEP) field staff.

NLEP staff invited people affected by leprosy to collect their supplies from a number of central distribution points. 294 people received supplies in the Khargone district and another 195 in Barwani district. The remaining supplies were delivered to 61 people who live in the remote

When people with leprosy are caught up in emergencies, such as the Covid-19 pandemic, they are often among those most at risk. Not only are people with leprosy likely to be living in some of the world's most deprived communities, they may have already lost their livelihoods due to severe disabilities and are



tribal districts of Jhabua and Alirajpur, despite the fact that it took several days to reach them. In total, 1,010 people were helped by this joint initiative, including both people with leprosy and their families.

The Guild would like to thank our supporters for enabling us to help some of the most vulnerable people on the planet in their hour of need.

In memory of Mr Robert Mark Hatcher

Mr Robert Mark Hatcher, known to his family as Mark, kindly left a gift in his will to St Francis Leprosy Guild when he died in 2019. His family did not know that he had chosen to support people with leprosy but it was characteristic of his lifelong consideration for others, especially those less fortunate than himself.



Born and brought up in Byfleet, Surrey, Mark attended St Andrew's University where his affection for

Scotland first began. Having retired in 1992, it was not until late 2016 that Mark returned to live in the Scottish Borders. The decision to move to Scotland was completely vindicated with his great happiness and joy of

living in beautiful surroundings, with a warm welcome from neighbours, parishioners and local clubs in which he took a great interest. But the dream was brutally cut short as, sadly, he was diagnosed with motor neurone disease just two years later.

Mark was a man of great integrity, talents and accomplishments; the fact that he touched many is recorded on his gravestone in Jedburgh. It reads that he was a "Devoted and beloved son, brother, brother-in-law, uncle, great uncle, and friend to many." He was certainly a friend to the Guild.

Mark's name will live on in our Book of Remembrance and we will continue to remember and pray for him at our Annual Mass, along with all the many benefactors who have supported so many leprosy sufferers over the years.

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 make a big difference.

If you would like to know more about how to leave a gift and all the good it can do, please call our Administrator, Sheila Pereira, on 07754 592240 or you can email administrator@stfrancisleprosy.org. She will be happy to send you more information or answer any questions you may have.





Obituaries

Nicholas Hall

Nicholas Hall joined the Board of Trustees at St Francis Leprosy Guild in March last year, and sadly died very suddenly only nine months later on 7th December 2020.

After attending Ampleforth School and Cambridge University, Nicholas became a successful commercial and financial services lawyer, working in the City, Europe and Asia until his retirement in 2017. He attended four Board meetings via Zoom during the pandemic, quickly becoming an invaluable member of the team. Nicholas joined the Guild just as we were changing our charitable status and embarking on a new operational strategy. His advice was indispensable in steering the best course for the Guild and furthering our goal of accelerating towards a leprosy-free world. The work he did in enabling us to provide a Covid-19 emergency food project in India and to become an Associate Partner of the Leprosy Research Initiative have also advanced that cause significantly. We are greatly saddened by his death.



Sr Anne Curtin MMM



Sr Anne worked as Honorary Secretary for St Francis Leprosy Guild between 2001 and 2013, before retiring to the motherhouse of the Medical Missionaries of Mary at Drogheda, Dublin. After joining her order at 20 years old, Sr Anne trained as a nurse, specialising in ophthalmic nursing at Moorfields and obtaining a diploma at the London School of Hygiene and Tropical Medicine. Her practical experience of treating leprosy in Nigeria was invaluable when she came to assess grant applications on behalf of the Guild. Sr Anne had also been the administrator to Abakaliki Hospital in Nigeria, a place dear to her heart and a leprosy centre that the Guild still supports today. May she rest in peace.

The past year in figures

The following charts show the Guild's voluntary income for the year Jan - Dec 2020 and also how that income was used to provide grants to partner organisations across the world.

†**SFLG** ST FRANCIS LEPROSY GUILD

Full accounts will be available in due course on the Guild website: www.stfrancisleprosy.org and on the Charity Commission website: www.gov.uk/government/organisations/charity-commission charity number 1188749
Please note that, since we became a Charitable Incorporated Organisation in May 2020, The Charity Commission have requested that the accounts we submit to them cover only the period 25 March 2020 - 31 December 2020.

Income 2020

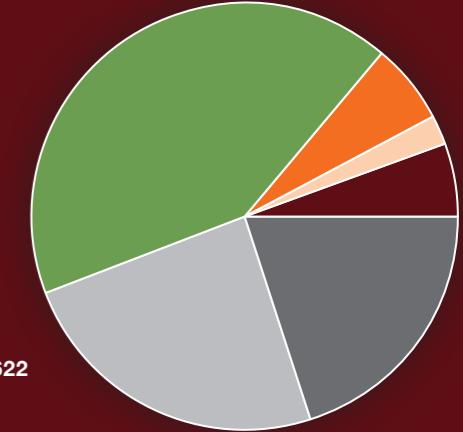
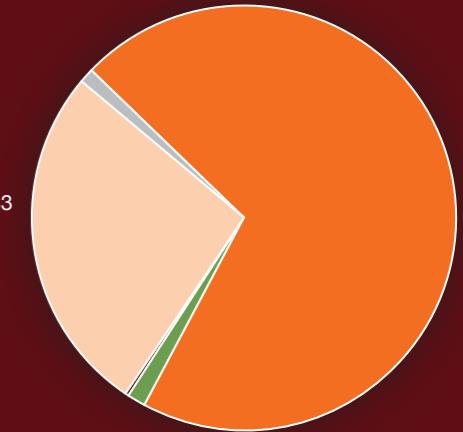
Donations £130,307
Church collections and donations £3,683
Legacies £345,571
Trust income £6,550

Total voluntary income 2020: £486,111
 Other: £882

Expenditure 2020

India (£61,390)
South East Asia (£36,500)
South America (£10,000)
Africa (£30,500)

Total grants awarded in 2020: £138,390
 Project Support £109,921
 Donor Support £135,311
Total resources expended in 2020: £383,622





Tel: 07754 592240



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



Global Partnership for
Zero Leprosy



LEPROSY RESEARCH INITIATIVE



Registered with
FUNDRAISING
REGULATOR

