

The end is in sight in fight



Catholic charity St Francis Leprosy Guild is striving to see leprosy eradicated within 25 to 30 years, writes **Jason Osborne**

Leprosy, or Hansen's disease, has stalked the world since biblical times, and God has often used it to show that his healing power is at work in the world. He transformed the appearance of Moses' hand to a "snowy" white, before healing it moments later, and Jesus healed many of the affliction during his time wandering the earth.

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More recently, God continues to minister to those who suffer from the disease, although now he does so through the goodness of those who give up their lives to fighting it. Such saints as St Damien De Veuster (better known as St Damien of Molokai) and St Marianne Cope (also of Molokai) dedicated their lives to those living with leprosy, with St Damien himself succumbing to the disease.

Today, Catholic charities like St Francis Leprosy Guild continue their work, and it's a work that's truly bearing fruit, with leprosy on the cusp of defeat.

Speaking to *The Irish Catholic* newspaper, CEO of St Francis Leprosy Guild, Clare McIntosh explained that while the charity is small, it's making waves in the fight against leprosy, changing its strategy to meet the needs of an often-ailing world.

“So our direction has been a little bit different since 2017... People with leprosy were the poorest and the most excluded people in society, so once you showed signs



A woman suffering from leprosy waits for treatment inside a clinic in Siliguri, India. Photo: CNS

of leprosy, you were completely pushed out,” Ms McIntosh explains.

“And so, there wasn't a cure until the 1980s, so the money at that time went to helping people, treating their condition as best as possible, helping with poverty, helping to integrate them. But in the 1980s, a cure was found to leprosy and as of 2017, we decided that our strategy should really be about ending leprosy, so not just helping people that have it, but actually ending leprosy altogether.”

Catholic heritage

St Francis Leprosy Guild is an organisation well suited to carrying out the task of eradicating leprosy, with a Catholic heritage, as well as one of scientific expertise.

“We have a trustee board of 12 people, all of whom are Catholics. Among our trustees, we have some very credible people, such as Professor Noel Gill, who is an epidemiologist, and he was responsible for the HIV strategy in the UK. Interestingly, relating back to that time,

in the 1980s, HIV wasn't very well understood, and one of the things he did, and he published a paper, was whether HIV could be transmitted through the Communion cup. It's interesting, but he went on from that to lead the HIV strategy in the UK, and he's also part of the Covid team in the UK, so we have him.

“The ‘R’ in TRACE stands for ‘research’, and sees the charity partnering with the Leprosy Research Institute (LRI) which is a global organisation seeking to end leprosy”

“We also have Professor Robin Graham-Brown, who is a professor dermatologist. So, even though we're a small charity, we are very well informed by that level of

scientific expertise. We've had a long relationship with the FMM's (Franciscan Missionaries of Mary) nurses and also the Medical Missionaries of Mary, and that relationship goes back right to the very beginning.

“We have a sister that sits on our trustees, also. Then the remainder of the trustees are a mixture of foreign office background diplomats and so on who've actually served in different countries, and we have an accountant and so on.”

Strategy

Armed with faith and scientific expertise, the charity has its eyes raised to the heavenly ideal of eliminating leprosy, while keeping its feet on the ground through concrete strategy and work. TRACE is the watchword by which they tackle the disease, embodying a strategy which is proving most effective in the total reduction of leprosy from the global community.

“We currently have five parts to our strategy which we call TRACE.

So, 'T' is about training, and effectively, from a global perspective, leprosy is considered eliminated if less than 1 in 10,000 people in the population have it. That means that globally it's eliminated, and it's eliminated in lots of countries, but in reality, even if you're less than 1 in 10,000, there can still be a lot of people with leprosy,” Ms McIntosh says.

“So for example, in India last year, there were 160,000 people diagnosed with leprosy, but when elimination was declared, a lot of countries stopped investing in leprosy, which means that a lot of the skills to diagnose leprosy have gone away, so the 'T' in our training is all about how do we help these countries train enough people that leprosy might be cured.”

The 'R' in TRACE stands for 'research', and sees the charity partnering with the Leprosy Research Institute (LRI) which is a global organisation seeking to end leprosy. Technology is often put to its best use in the area of medicine,

against leprosy

and that's precisely the avenue down which St Francis Leprosy Guild is looking to travel, taking a lead from all of the technological input during the pandemic.

"A current project that we are sponsoring is having smartphone technology they can take into the field, where they can record any development of symptoms, they can look at any symptoms to see what's happening and record the contact data. Because leprosy is contagious, but it can take three to five years to develop, you need to keep a contact history of people – when were they last seen, what was observed, and so on. A smartphone application will help to record that."

“All of this work is incredibly valuable, but the Church has always understood that the work takes on another dimension altogether when done with God in the heart”

Of course, to combat leprosy, you have to find those suffering from it, people often found on the margins of whichever society they find themselves in.

"A' is 'active case finding', and that's, of all the things in TRACE, that's the biggest one that we're focused on. So that's, rather than waiting for people with leprosy symptoms to come to us, we're

actually trying to go out into the remote villages and diagnose it early," she says.

"There's some fascinating stories there. One of the projects we fund is a doctor, Dr Tony, it's on our website, and she has a hospital boat in Brazil that she takes up the Amazon, going to all these villages which are extremely remote and then diagnosing and treating leprosy as she finds it up there.

"C' the is 'care', and so that's continuing the things that we did do in the past, so having all these centres where we look after people with leprosy. Then 'E' is emergencies. Last year we sent food parcels to India because of the Covid crisis, and then at the moment we're very much thinking about, 'How do we respond right now to have the greatest impact?'"

God in the heart

All of this work is incredibly valuable, but the Church has always understood that the work takes on another dimension altogether when done with God in the heart. The organisation takes great "pride" in its Catholic ethos, looking to continue to work that countless nameless and faceless religious and lay people have done throughout the millennia since Christ left the struggle against evil in our hands, albeit with his guidance.

"The ethos is very much just helping people with leprosy as we find them. So, we're governed by Catholics, and it's a charisma that we are executing to try and help people globally, but we don't show any distinction based on race, religion, any other criteria," Ms McIntosh says.

"We try to take a pride in our Catholicism, because historically the Catholic Church has sent so many missionaries out into these countries who've committed their lives to doing good work, and I personally feel that we don't talk about that enough as a Catholic Church.

“On a more practical level, however, the emphasis on hygiene bodes well for the limiting of leprosy”

"I think we get far too much coverage of the negatives that go on, but actually the commitment that these people show is just amazing. We are proud of our Catholic background, but then we help anybody that needs to be helped. As we say, our focus is very much on the actions we can take to end leprosy for good. We want to manoeuvre on from managing the symptoms to actually doing the research and training so that we can actually end this for good."

Earlier in the year, Ms McIntosh told this paper about the way Covid-19 was weighing in on the battle to reach and help those struggling with leprosy, and she continues to acknowledge some of the good the pandemic has done while fully aware of the ways in which its made their job more difficult.

An ability to mobilise a wealth of resources in a single direction, such as has been done by the governments and organisations of the world during the pandemic, has given hope to all of



St Damien de Veuster is pictured in bed shortly before he died in 1889 at the Kalawao settlement on the Hawaiian island of Molokai. Photo: CNS

those fighting seemingly 'perennial' diseases. On a more practical level, however, the emphasis on hygiene bodes well for the limiting of leprosy.

"The big focus on hygiene has been helpful. Obviously, a big thing with Covid is being able to wash your hands, but if you're in a village which has no running water, how do you do that? I think there's a growing recognition there's underlying hygiene measures that help against all diseases," Ms McIntosh says.

“Many diseases that have plagued humanity for thousands of years will unfortunately likely still be around for a long time yet, but the elimination of leprosy is ‘tantalisingly close’, in the organisation’s words”

However, one of the greatest areas of ignorance in many communities around the world today is on the societal level, of the societal effects leprosy has on those who suffer from it.

"I think a key thing with leprosy is the stigma, and it's hard, particularly in this current environment of things like Black Lives Matter and so on, where we look at unconscious bias and things like that – it's hard for people to relate to societies where it's institutionalised. In some countries you can divorce somebody because they have leprosy or fire someone or exclude them from school, and so that's not just badly thought through behaviours – that's actually how their society exists," she says.

"It's interesting; I read a story recently in the press about a father of a boy with autism who had gone out without a mask, and he'd gone into a shop and the shop said they have to leave. He was trying to explain that his

son with autism wasn't able to wear a mask, and in the interview, he said, 'It's not as if he's a leper'.

"Again, that amazed me, that even in our language, even though we don't come across leprosy so often, the fact that he said that implied that had he had leprosy, that would have been an acceptable treatment. The stigma around leprosy is just very, very ingrained. We're trying to increase awareness of that, in the next few months particularly.

"There are cases where people have been literally left by their wives, abandoned entirely by their families, their families will never have contact with them again. They're completely isolated. It's more than a disease, if that makes sense."

Normal life

"If you have cancer you're obviously very sick, and if you recover from cancer, you can regain a normal life, but what's different about leprosy is that even when we can cure the medical side, we can almost never completely reintegrate someone into society – that stigma lives on. That's why it's so critical that we do our programmes because the stigma lasts for life, so if we have a chance of avoiding that when someone's 17, the difference is they go on to live a full and valuable life verses being in a colony completely extricated from everybody."

For now, the struggle goes on, but as so rarely happens in this world, the golden end is in sight. Many diseases that have plagued humanity for thousands of years will unfortunately likely still be around for a long time yet, but the elimination of leprosy is "tantalisingly close", in the organisation's words.

"Our chair talks about it being 'tantalisingly close', so we really believe if we can work comprehensively we genuinely can end leprosy soon, and if the focus disappears, that end point goes further back. We hope to end leprosy in 25-30 years, but if we lose focus, it could be 150 years, so we just want to make sure that we don't lose that and keep the passion and the focus."



A religious sister dresses the foot sores of a patient at the Tai Kam leprosarium, located on a tiny island in China. Photo: CNS