The Lily Foundation

Impact Report 2024/25

Fighting mito, finding hope.

Our vision is for a world in which every mitochondrial disease patient has a voice and access to treatment, support to improve their life and, ultimately, a cure.

“Together we’re navigating the complexities of mitochondrial disease: today raising awareness of mito across the globe; tomorrow unlocking the cure through pioneering research; forever supporting the mito community and empowering everyone to make a difference.”

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About us

The Lily Foundation is the UK's largest mitochondrial disease (mito) charity. Our vision is for a world in which every mito patient has a voice and access to treatment, support to improve their life and, ultimately, a cure.

Mitochondrial disease is a rare, complex and difficult-to-diagnose genetic disorder that affects people in very different ways. It can affect any organ at any age and often occurs in babies and young children. Every other day in the UK, a baby is born who may develop serious mitochondrial disease. There is currently no cure.

Our charity was founded in 2007 by Liz Curtis in memory of her daughter Lily, who died from mito at 8 months old. Finding little in the way of specialist knowledge or support to help her through her ordeal, Liz set out to provide answers for herself and others in her situation.

What began as an informal network of family and friends has grown into a national charity that has raised over £11 million in the fight against mito. We work tirelessly to bring mitochondrial disease into the public eye, support the patients and families affected by it and fund cutting-edge research that will lead to treatments and, ultimately, a cure.

“This past year has marked significant progress for the mito community, from landmark scientific advances to the tireless efforts of supporters across the UK. Reflecting on all we've achieved together, I feel deep pride in our momentum and renewed hope for the road ahead.

It's been a remarkable 12 months for research, with the success of mitochondrial donation IVF, a cause we championed for years, and the approval of the first-ever treatment for one form of mitochondrial disease. Add to that the launch of the £7.5 million LifeArc Centre, our IMPACT patient panel and Research Zone, and the future looks bright.

Support remains at the heart of our mission. Our Adult Support Weekend has become a firm fixture in the calendar alongside our Family and Young Adult events, and we continue to offer both emotional and practical support through initiatives such as online counselling, virtual coffee mornings and Zoom Room webinars.

However, none of this would be possible without our supporters. To everyone who has run, walked, baked, boxed, danced, donated, cheered, held or joined a Lily event, thank you for making a difference as we continue to fight mito and find hope for everyone affected.”

LIZ CURTIS

The Lily Foundation founder and Lily's mum

Rachel's story

For many, deafness is simply the absence of sound. For Rachel, who was diagnosed with mitochondrial disease in February 2024 after decades of unexplained health issues, it's also been the loss of voice – not just the ability to hear others, but the struggle to be heard herself. For years, she stayed silent about the impact deafness had on her life. Until we gave her a voice.

"Knowing what I was facing didn't magically fix things, but it gave me something I'd been missing – clarity. Now, I understand why my energy is limited, why trying to hear is so exhausting, and how to better manage it. I've found support through specialists and through The Lily Foundation."

It was Rachel's genetic counsellor who first signposted her to The Lily Foundation. Rachel wasn't sure what to expect, but despite being terrified – having withdrawn from society for years – she forced herself to attend the Lily Adult Support Weekend.

"I'm so glad I did! I laughed, I made friends and I felt part of something. Since that weekend, the weekly Lily coffee mornings have brought joy and connection back into my life. I've found my voice again, and with it, a renewed sense of confidence and hope. I'm so grateful to everyone at The Lily Foundation for helping me feel seen, heard and understood."

Our year in numbers

1 mitochondrial disease treatment approved for use on the NHS

83 patients and family members tuned in to our first two Zoom Room webinars

We welcomed **222** patients, carers and family members to 3 support weekends

13 football stadiums visited by celebrity supporter Kevin Day as part of his 63-mile 'March of the Day'

8 babies born via mitochondrial donation IVF with no signs of mitochondrial disease

Over **£1.1 million** was donated by people like you

We funded a total of **230 counselling sessions** for individuals and 92 sessions for couples struggling to deal with mental health issues

Over **1500** families turned to us for support and guidance

85 patients signed up to our IMPACT panel to directly influence research

Online stats

135,034 pages of our website were viewed by 74,784 users

1476 members of our closed Facebook groups for families and adults

46,500 views of Research Zone-related content

24,918 people followed our news on Facebook, X, Instagram, LinkedIn and Tiktok

Advances in research

The Lily Foundation are the largest charitable funder of mitochondrial disease research in Europe. Research not only helps us to understand more about the complexities of mito, but it brings life-changing benefits to patients today, and holds the key to finding effective treatments and, ultimately, a cure.

Breakthrough in mitochondrial donation IVF brings hope to families

In July, we were thrilled to share a major breakthrough in the fight against mito: the early success of mitochondrial donation IVF. This is a fertility technique that allows families at risk of passing on the condition to have genetically related children free from faulty mitochondrial DNA.

Research was published confirming that eight babies had been born via the technique who showed no signs of mitochondrial disease, a milestone that represents real hope for families. The Lily Foundation has been part of this journey from the start, campaigning to change UK law back in 2015, sharing patient stories and ensuring the voices of families were heard throughout the process.

The story received an incredible amount of TV coverage including the breaking news story on the BBC News at 10, Sky News and ITV lunchtime news with Liz in the studio and ITV evening news at home with our Operations Manager Claire. There were also three local radio interviews with Katie, our Head of Patient Programmes, and numerous written articles mentioning us including BBC, Sky, Yahoo, The Guardian and The Sunday Times.

First ever mitochondrial disease treatment approved!

Just weeks after the news broke about the success of mitochondrial donation IVF, we found ourselves celebrating another huge milestone for the mito community. For the first time ever, a treatment for one form of mitochondrial disease was approved for use on the NHS in England.

Idebenone became available to help people living with Leber's hereditary optic neuropathy, one of the most common types of mitochondrial disease. The condition generally affects the optic nerve, leading to severe vision loss and eventual blindness, and the drug can help preserve vision and in some cases even reverse the decline.

Lily's Head of Patient Programmes, Katie, said:

"This is a huge win for the mito community and we're proud to have been a key stakeholder throughout the process. While it isn't a cure, this treatment offers real potential for patients to preserve or improve vision, giving the chance to regain independence, confidence and a better quality of life. And the fact that there is now a treatment available for mitochondrial disease brings hope for future drug development."

LifeArc Centre

Rare Mitochondrial Diseases

£7.5 million research centre for rare mitochondrial diseases launches
Another significant milestone for the mito community was the launch of the £7.5 million LifeArc Centre for Rare Mitochondrial Diseases in April. For the first time, the UK's leading mitochondrial specialists are working together at this scale, sharing expertise, data and cutting-edge technology.

Led by Professor Patrick Chinnery from The University of Cambridge, the 5-year project is a partnership between LifeArc, a self-funded medical research charity, ourselves and Muscular Dystrophy UK (MDUK).

The pioneering centre will bring together leading researchers, clinicians, infrastructure and patient communities across the UK to focus on three key areas – speeding up diagnosis, identifying biomarkers and developing new treatments.

Importantly, The Lily Foundation are leading on Patient and Public Involvement and Engagement (PPIE), ensuring that the voices of patients and families will be embedded in every part of the centre's work and lived experience guides the direction of research.

Lily Precision Medicine Diagnostic Project

The Precision Medicine Diagnostic project is currently at recruitment stage, while starting to deliver the first diagnoses to patients. Sites for recruitment have opened at UCLH (London), Oxford, Northern Care Alliance, Manchester, Moorfields, Birmingham, GOSH, Guy's and St Thomas' and Cambridge. In the coming months sites will open in Sheffield, Sandwell and West Birmingham, Newcastle and Bristol.

The project is expected to increase rates of diagnosis of mitochondrial disease by an additional 20%. Currently, 112 patients have been recruited, with 9 confirmed diagnoses to date and 2 novel genes under review.

Experiences of Diagnosis Study

During April and May, we ran our first Lily-led piece of research, the Experiences of Diagnosis Study. This study was commissioned directly from discussions within our PPI (Public & Patient Involvement) group for the Precision Medicine Diagnostic Project. The discussions highlighted significant variability and inequality in the diagnostic experience – concerns also echoed through anecdotal reports to The Lily Foundation.

The study aimed to recruit 100 participants, and we exceeded this target with 172 responses, of which 103 were included in the final analysis. The research identified five key themes outlining improvements needed to enhance diagnostic pathways across the UK. A second phase will follow, with the overall goal of publishing gold-standard recommendations in a high-quality peer-reviewed journal and sharing the findings widely through our channels.

RESEARCH ZONE

Introducing The Lily Foundation Research Zone

In January we were thrilled to announce the launch of our Research Zone, a vibrant space dedicated to showcasing the latest in mitochondrial disease research.

Patients and families in our community have often told us that finding accessible, reliable information about mitochondrial disease can be a significant challenge. Mito is complex and poorly understood by both the public and those affected, and many patients and families struggle to access clear, digestible details about the condition.

That's where our Research Zone comes in – bridging this gap and providing the latest breakthroughs, expert insights and cutting-edge developments in mitochondrial disease research in an engaging way for patients, caregivers or even those simply passionate about science.

Since launch, there have already been over 46,500 views of Research Zone-related content across multiple platforms, proof the content is being well received.

Research on the road

This year, our Research Team took a strategic approach to conferences, clinical study days and patient information events, focusing on those most relevant to the mito community while continuing to raise awareness of our work.

We attended 13 events across the UK and Europe, and at each event we presented Lily-led research and contributed to panel discussions on science and patient advocacy. These occasions also created valuable opportunities to build relationships that will be essential as new therapies for mito begin to emerge.

Representing patients at the ENMC
In November, The Lily Foundation took the views of more than 70 people with primary mitochondrial myopathy (PMM) to the European Neuromuscular Centre (ENMC) workshop in the Netherlands. Patients had shared feedback on symptoms, trial design and participation, which we presented directly to international researchers, clinicians and industry leaders. Those patient voices have shone a light on how clinical trials should be developed to be more relevant, accessible and patient-friendly.

Putting TK2d in the spotlight: why patient voices matter

Our Head of Patient Programmes, Katie, presented new research at the European Paediatric Neurology Society (EPNS) conference in Munich. The findings came from the Assessment of TK2d Patient Perspectives (ATP) study, a global project shaped by both clinicians and patients which looked at the real-life impact of TK2d on those living with the condition and caregivers.

The research revealed that TK2d, an extremely rare form of mitochondrial disease, places a significant burden on individuals of all ages, no matter when symptoms begin. Across the board, patients described debilitating physical challenges as well as serious psychological strain that profoundly affect their everyday lives and overall wellbeing.

These insights will help inform a patient group submission to NICE (the National Institute for Health and Care Excellence), supporting the review of a potential treatment for TK2d. The Lily Foundation have teamed up with Metabolic Support UK and Genetic Alliance UK to ensure that real stories and lived experiences are at the heart of the submission, highlighting what matters most to patients.

"Being part of the focus group has enabled me to share experiences with other families, bounce ideas off each other and help in shaping the way forward for families impacted by mitochondrial disease."

- Steve, IMPACT participant and mito parent

The patient voice

33 IMPACT members actively contributed to 6 research projects

Making an IMPACT in the fight against mito

Although scientists, doctors and researchers have a lot of knowledge about mitochondrial disorders, it's patients who know what it's like to live with the disease. Their input can help shape the ideas of clinicians and researchers, allowing them to ensure their work is relevant, good value for money and useful to the mito community.

That's why, after last year's success of our pilot Expert Patient Input Committee (EPIC), we were delighted to announce its evolution into something bigger and better – IMPACT! Our Mitochondrial Patient Advisory Committee is a virtual panel made up entirely of people affected by mito who are willing to share their experiences to help shape research, clinical care and treatments.

Projects have ranged from developing a patient toolkit to improve research communication to designing an interview study exploring how women with mitochondrial DNA mutations view their reproductive options.

Support Services

A place to connect
Membership of our private Facebook groups continues to grow, with membership of the Family Support Group up 12% and the Adult Support Group up 16%.

"It feels so good to at long last be amongst people who understand"

- Adult mitochondrial disease patient

A safe space to talk
Demand for our online counselling service continues to exceed capacity, showing just how vital mental health support is for people affected by mito.

Thanks to our partnership with Rareminds, we were able to fund 230 counselling sessions for individuals and 92 sessions for couples, giving those affected a safe space to cope with the challenges of mitochondrial disease.

Rare disease 'passport' launched for mito patients
We joined forces with Cambridge Rare Disease Network (CamRARE) to offer the 'This is Me' Rare Patient Passport, a powerful tool that helps patients and carers share essential medical information quickly, whether in an emergency or when meeting a new healthcare professional.

Providing a concise view of a person's medical history and care needs, this clever tool is designed to address the unique needs of individuals with rare conditions like mitochondrial disease, helping to overcome the challenges of having to explain a complex condition quickly.

So far CamRARE have received 186 applications via The Lily Foundation – the highest of any patient group they partner with!

Living well with mitochondrial disease: Lily Zoom Rooms
We launched our Zoom Room webinars, a series of online sessions hosted by professionals designed to help families navigate the day-to-day realities of living with mitochondrial disease.
83 guests tuned in to the first two sessions, with a further 322 views via YouTube where the recordings are available for those who couldn't join live.

"Excellent seminar and please keep going with this. Looking forward to the next one."

- Adult mitochondrial disease patient

Putting mito on the map

World Mitochondrial Disease Week was a huge success, with a host of activities, and notable media coverage, taking place up and down the country thanks to so many of our supporters embracing our mission to put mito on the map.

8 hard-hitting facts about mitochondrial disease that were shared hundreds of times

13 football stadiums visited by celebrity supporter Kevin Day as part of his 63-mile 'March of the Day' across London which raised £7,000

30 people who signed up to Take a Stand against mito

224 supporters who changed their social media profile pic for a twibbon

100s monuments that were lit up green across the globe

1000s followers who engaged with us on social media

Laughter and generosity at our first northern Comedy Night!
Our first-ever northern Comedy Night at Manchester's legendary Frog & Bucket Comedy Club was a resounding success, raising £4,000 to help fund vital research and support families affected by mitochondrial disease.

The packed-out event, which sold out just weeks after tickets were released, saw a star-studded line-up of comedians take to the stage, headlined by Jon Richardson and Josh Jones.

Founder and Lily's mum Liz said:

"It was a fantastic night – we couldn't have asked for a better audience, a more talented line-up or a more iconic venue! A huge thank you to everyone who came along and supported us in our first foray up north."

When teams come together, incredible things happen
At Portsmouth High School, the power of a united community made a real difference in the fight against mito. Led by Sixth Form students, the school ran a year-long fundraising campaign in memory of Otto, son of alumna Millie, raising over £13,000 for The Lily Foundation.

From talent shows and live music to netball matches and a fashion show, the funds raised from their creative and varied campaign will support the Lily Precision Diagnostics Project, helping families access faster, more accurate genetic diagnoses.

Hitting the right notes for Lily
When the organisers of the 2025 Battersea Jazz Festival announced that they wanted to support The Lily Foundation, it was music to our ears! A fantastic opportunity to reach a new audience, this annual celebration of jazz brings together international talent across venues in Battersea, Clapham and Nine Elms. With £1 from every ticket, plus donations, a total of £1,833 was raised to support our work.

Goldsmiths Choral Union supported us at their traditional Christmas carol concert for the second time. Taking place at Holy Trinity Church, London, the sellout event was attended by members of the Lily team who raised awareness of our work and collected a total of £1,208 in donations.

Finding a platform to start spreading the word
When Maddie was diagnosed with mitochondrial disease at just 22, she and her family were left feeling overwhelmed and alone. It wasn't until they attended their first Lily event that they found what they desperately needed: hope, understanding and a community that truly "got it."

Since then, Maddie and her parents, Kay and Paul, have turned their fear into purpose. From seeking out research opportunities to raising awareness and bringing new supporters into the fold, they've discovered a powerful sense of connection and a platform to make a meaningful difference.

Raising awareness in memory of Sophie
When mito patient Sophie's classmates at Kempshott Junior School in Basingstoke learned of her passing, they wanted to honour their brave friend. The children took on a 7km memorial walk – one kilometre for each year of Sophie's life – raising awareness and over £3,000 to support The Lily Foundation.

"It was great to see her classmates pay tribute to our wonderful Sophie and also learn about mitochondrial disease," said Sophie's mum, Sarah. "We want to not only raise awareness of this terrible disease but also… highlight the tremendous work of The Lily Foundation, who work tirelessly to offer hope to sufferers and their families, and strive to improve diagnostics and ultimately find effective treatments. We cannot thank them enough for the support they have offered us."

Isle of Wight couple's epic pilgrimage for mito
Dedicated couple Linda and Paul from the Isle of Wight walked from Canterbury to Rome – a 1,250-mile pilgrimage route they completed in just 93 days, inspired by 3-year-old Teddy, who lives with mitochondrial disease.

The couple set off from Canterbury Cathedral in May, raising awareness and funds along their epic route which took them through England, France, Switzerland and Italy to their final destination of Rome.

87 days on the Via Francigena

10 rest days

1,205.3 miles walked

614 hours and 28 minutes on foot

But this journey was more than just statistics. The couple raised an impressive

£2,779
including a generous anonymous donation of £1,000.

India's story

22-year-old India began showing symptoms of mitochondrial disease when she was just nine. She also lives with dystonia – a neurological movement disorder that causes painful, involuntary muscle spasms and contractions – and this adds another layer of complexity to her daily life.

"Both the dystonia and my mito now constantly affect my daily life. It felt really frustrating to lose my independence, but I also lost all my friends, which was difficult to deal with, especially at a young age. As an adult, I still feel quite lonely and have lost a lot of confidence."

The physical impact of dystonia and mitochondrial disease is relentless, and India currently manages her condition with a combination of medication, physiotherapy, Q10 supplements and botulinum injections. But it's the emotional toll that's often overlooked.

"The Lily Foundation gave me access to counselling. That's helped me learn how to manage anxiety and try to accept the uncertainty. I also join the weekly coffee mornings, which are a great way to connect with others who understand and to even make friends."

We couldn't do this without you

London Marathon

36 runners together raised an incredible

£125,000

including Joe and Leo, who each clocked up over £12,000!

The Big Lily Bid

The Big Lily Bid, our online auction that ran for a week in March, raised more than

£8,000

Items included Meet & Greet tickets to Peter Kay's sold-out UK tour and a pair of Adidas trainers owned and signed by One Direction's Niall Horan.

Teams Fundraising

62 fundraising teams came together to raise

£215,948

Lily Skydive

At the first ever Lily skydive weekend, 12 thrill seekers raised over

£10,000

Run for Charity

Thanks to our partnership with Run for Charity, 32 representatives took part in 8 new races, raising over

£12,000

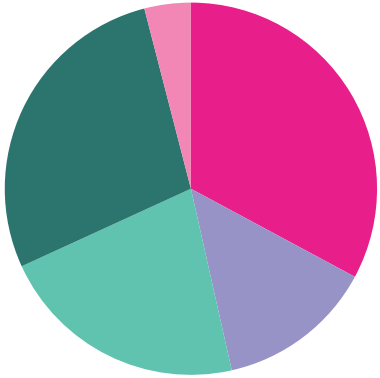
Sunny skies and big smiles at London Landmarks
Team Lily brought energy, determination and heart to the London Landmarks Half Marathon in April. 34 runners turned out in Lily colours, including founder Liz, her partner Dave and their daughters Katie and Rosie. The quartet had signed up to mark what would have been Lily's 18th birthday and honour her legacy, and they were joined by Lily's auntie, Helen, and her cousins, William, Isabel and James.

But this was more than just a family affair. Numerous parents and supporters also took part, as well as the charity's Chairman, Ben. The Lily spirit was out in full force along the route with an animated cheer squad waving banners, wielding clappers and spurring everyone on to the finish line.

The day was emotional but also uplifting for Liz, who said afterwards:

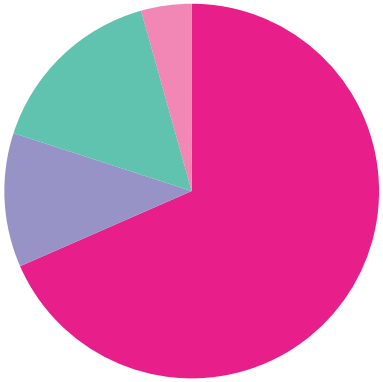
"What made it even more special was that it wasn't just us out there. So many mito families were running for loved ones, or in memory of someone special. The sun shone, the atmosphere was incredible and we had amazing support along the way. A huge thank you to everyone who ran, cheered or donated to our total pot of almost £30,000."

Income and expenditure Summary



- Voluntary income & donations (£359k)
- Lily fundraising (£149k)
- Grants (£237k)
- Sports events (£304k)
- Sundry (£44k)

Total income - £1,094k



- Charitable expenditure (£739k)
- Fundraising trading costs (£125k)
- Generating voluntary income (£169k)
- Governance costs (£47k)

Total expenditure - £1,079k

We spent 70p of every £1 raised on charitable expenditure.
These figures are estimated and have not been audited therefore may be subject to change.

Our vision for the year ahead

2026 is shaping up to be an exciting and ambitious year for us – one that will bring new challenges, fresh breakthroughs and, we believe, even more reasons to feel positive.

One major highlight is the launch of The Lily Foundation Guide to Mitochondrial Disease. This simple-to-understand resource, created in collaboration with experts in the field, addresses a critical need for accessible information, and will provide invaluable support to newly diagnosed patients and families as well as those further along their mito path.

We'll also be kicking off plans for a hugely ambitious, £25 million Research Institute – the first of its kind in the field of mitochondrial disease anywhere in the world. By uniting the UK's world-leading expertise in mitochondrial disease research, our goal is to collaborate over the next 10 years to accelerate the search for a cure.

Alongside the return of the popular Lily Gala Ball, we'll be back up to Manchester for our second Northern Comedy Night. We're also exploring a high-impact coast-to-coast cycling fundraiser for corporate supporters as well as new events and venues across the UK to help us reach more families and supporters nationwide.

These initiatives, combined with your continued support, will ensure 2026 is a year of celebration, growth and progress for both the mito community and The Lily Foundation.

Fighting mito, finding hope.

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