



The Lily Foundation

Impact Report 2023/24

Fighting mito, finding hope.

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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 an incredible £10 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.





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As I reflect on the past 12 months, I'm filled with pride at the incredible progress we've made together. Our community's dedication and strength continue to drive meaningful change in our mission to support those affected by mitochondrial disease.

Support remains at the heart of everything we do, and this year we've been able to expand our services in exciting new ways. We introduced free online counselling, ensuring emotional support is more accessible than ever, and hosted our first ever residential weekend dedicated solely to adult patients – a milestone for our community.

Our commitment to advancing research has never been stronger, and we've invested around £250,000 in three major new studies this year. Later in this report, you'll meet Jamie, a talented PhD student and the latest Lily-funded researcher working on our Precision Diagnostics project. You'll also read about the launch of EPIC, our virtual committee dedicated to giving mito patients a voice in research.

None of this would be possible without your generosity, dedication and belief in our mission. Whether you've volunteered, donated, fundraised or shared our message, your support is our driving force. Thank you for being part of our community as we continue to fight mito and find hope for everyone affected.

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LIZ CURTIS

The Lily Foundation founder and Lily's mum



James's story

James is 27 years old and lives in Gloucestershire with his family. He was diagnosed with LHON+, a type of mitochondrial disease, back in 2014 when he lived in Sydney, Australia.

"I was diagnosed with LHON+ in 2014 at the age of 16 in Sydney, where I used to live. This genetic disorder has left me with reduced vision and virtually no balance, so I use a mobility scooter to get around independently... Apart from that, I'm a normal person!"

After discovering The Lily Foundation over three years ago, he's attended events including our Gala Ball and Young Adult Weekend. It's the sense of community and the chance to mix with others who understand him that has helped James to find a place where he belongs.

"I really enjoy these weekends because I get to meet so many fantastic people. Everyone is really friendly and nice. Just to have the opportunity to meet others with the same condition, and having the understanding, that's what I find is really helpful to me."



Our year in numbers

Over
1300
families
turned to us for support
and guidance

We welcomed
307
patients,
carers and
family members
to our support weekends

Over
£1,180,000
was donated by people
like you

We invested
£329,488
into mitochondrial research

24
patients
got involved in our EPIC
panel to directly influence
research

Our Research Team raised
our profile at
13 conferences
around
the world

We funded
128
counselling
sessions
for patients struggling
to deal with mental
health issues

We helped patients access
£36,848
of benefits support

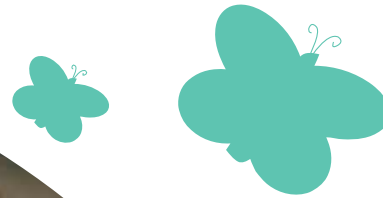
22,100
people followed our news
on Facebook, X, Instagram
and LinkedIn

6243
patients accessed information
on our website's mitochondrial
disease Q&A page

and
1 National Lottery
Local Health Hero
Award for our founder,
Liz, at The Sun's Who
Cares Wins awards



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.

Relief for balance issues in mito patients

Back in 2020 we funded a research study aiming to develop a framework to help identify the cause of balance problems in people with mitochondrial disease. That study is now complete, and the questions in the framework have been shown to accurately rule in or out vestibular (inner ear) causes of imbalance and dizziness in mito patients.

Vestibular testing is currently very specialist, and waiting lists can be long, but thanks to our funding and the team's hard work and dedication, mitochondrial disease patients should now be able to access treatments relatively easily, with positive results.

"It was amazing to have Lily's support... and, of course, we're hugely grateful to those people living with mitochondrial disease who gave up their time and energy to consider, support and participate in the study."

- Sarah, physiotherapist and research lead, UCL

“It’s never too early to see what’s possible and who you might inspire.”

Introducing our newest research recruit

Meet Jamie – the latest Lily-funded researcher to join our team working to better understand the complexities of mitochondrial disease. The work she’s involved in, as part of our Precision Diagnostics Project, is vitally important in securing a genetic diagnosis of mito for patients, and the role was a perfect fit for her.

“The more I read about mitochondrial disease, the fact that it’s so challenging for patients, and the fact that I could use what I really love and am skilled at, the more I wanted to do it. And learning about the charity inspired me. I wasn’t aware of how it first came about, but now that I know, I feel honoured to be in this position.”

Jamie’s very aware of the challenges faced by those affected by rare diseases such as mitochondrial disease, and the need to increase awareness. She’s also keen to inspire the next generation the way she was inspired by her biology teacher.

“I’d love to go back to school and spread the word about what I’m doing. My partner’s a teacher, and the school want me to come and talk to some of the students, so I’m already thinking about that. It’s never too early to see what’s possible and who you might inspire.”



£77,951



Finding hope for MNGIE patients

This year, we've invested nearly £80k into a project that could potentially alleviate symptoms for patients diagnosed with MNGIE, a type of mitochondrial disease syndrome. If successful, this trial could offer a safer and more affordable treatment option than current therapies, which can cause severe immune reactions or other side effects. It's a treatment that has the potential to significantly improve symptoms and even halt the progression of the disease.

"It will allow us to embark on an exciting and novel avenue in the development of advanced therapies for mitochondrial disease."

- Dr van den Aamele, project lead

£22,639

Better understanding of the patient experience

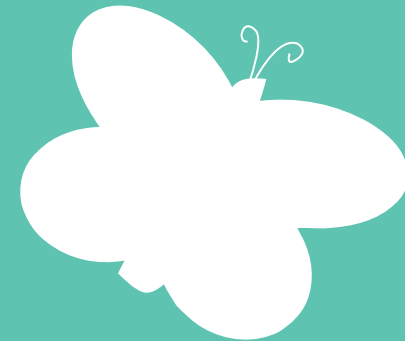
The team at Newcastle are working on improvements to PROMs (Patient-Reported Outcome Measures) to ensure they can accurately continue to collect valuable data whilst making it easier and safer for patients.



£77,734

Funding wearable tech to improve balance issues

Mitochondrial disease often causes balance issues which can lead to patients falling. That can mean additional pain and distress, so we're investing over £70k in a new research study to develop wearable technology that could enhance balance and ultimately improve quality of life for patients.



£94,315

Fuelling breakthrough research

We've also invested almost £100k into a pioneering new project by a team of researchers to investigate the effects of different treatments on mitochondrial diseases. The project, taking place at Northumbria University, will examine three possible methods of treating the disease that have all shown promise in mouse models.

£56,849

Significant advances in Lily-funded Precision Diagnostics project

Two years ago, we proudly launched a pioneering research project, investing over £750,000 in a study aimed at improving diagnostic rates for complex cases of mitochondrial disease. Today, the Precision Diagnostics project is moving at pace.

Recruitment sites are now open at both UCLH and Cambridge, with additional sites set to open over the next few months. We've also invested this additional funding into the project for a Senior Translational Clinical Scientist.

Using cutting-edge data analysis and bioinformatic techniques, the project will help patients still waiting for a confirmed diagnosis due to bottlenecks in existing diagnostic pathways. This research will contribute to our broader understanding of mitochondrial diseases too, helping to guide patient management and bringing us closer to potential treatments and, ultimately, a cure.



“Having a genetic diagnosis is crucial for families affected by mitochondrial disease. It gives them certainty, helps them plan for the future and opens up options for prenatal testing during pregnancy and IVF procedures for subsequent children.”

- Dr Maria O'Hanlon, Research Manager
at The Lily Foundation

Support services



A weekend of wellbeing

Our Family and Young Adult Weekends are staples in the Lily calendar, but feedback from the adult mito community told us that they were desperate for their own event. We were delighted to host our first Adult Support Weekend in August, a wellbeing-focused event offering 26 adult patients and their carers a safe, relaxed environment to meet others in similar situations, share experiences of their illness and create lasting friendships.

“The weekend meant the world to me. It completely changed my life.”

- Rachel, mitochondrial disease patient

A place to connect

Membership of our private Facebook groups continues to grow, with membership of the Family Support Group up 4% and the Adult Support Group up 9.6%.

The biggest... and best yet

64 families made their way to Warwickshire for our biggest Family Support Weekend ever, joined by an energetic team of medics and Lily volunteers.

“The Lily Family Weekend is so special, it takes away the mito isolation, and you make friends for life.”

- Samuel, mitochondrial disease parent

Wishes granted

Over £44,000 in grants was awarded to 28 families through the Lily Wish Fund. We contributed to short breaks, a home gym, a power recliner sofa, several scooters and buggies and a set of noise-cancelling earphones.

“The break made a huge difference... It gave us space and time together that wasn't interrupted by appointments. We were able to have conversations together and enjoy being together and Ahnie loved meeting Father Christmas... Having these memories is just so precious.”

- Francesca, mitochondrial disease parent

A safe space to talk

In January 2024 we launched a free online counselling service in partnership with Rareminds for individuals and family members affected by mito. Whilst demand has outweighed supply and we currently have a waiting list, we've been able to provide 128 confidential sessions to 21 patients or loved ones so far. 4 out of 5 felt more resilient following the support, while 3 out of 5 felt less isolated.



The patient voice

4 EPIC projects 24 EPIC participants

Something EPIC arrived

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, in October, we launched our Expert Patient Input Committee (EPIC), a committee 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 been around topics as diverse as exploring the diagnostic experiences of patients and understanding patient attitudes towards first in-human gene therapy trials.

"Honestly, I think any researcher would feel very grateful to have the EPIC resource and the level of support that you guys are bringing is remarkable."

- Dr Will Macken, Academic Clinical Lecturer at UCL

"Being part of this has really helped me feel like I'm doing something to help find cures and treatments for people with mitochondrial disease. It also makes me feel like I'm doing something good for myself and for other people that are affected by mito. I like the fact that I can air my views and the way I feel about medical research and take part in different research trials around the world, and it gives me a sense of belonging knowing that the community's out there and that Lily are working on behalf of us but also with us."

- Adam, mitochondrial disease patient



X Putting mito on the map

World Mitochondrial Disease Week was a roaring success, with a host of activities 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

100 – adventurous bears who took part in our ‘Share a Bear’ campaign to spread their mito message as far afield as the south coast, Yorkshire, Scotland, Dublin and Norway

230 – supporters who changed their social media profile pic for a twibbon

over 300 – monuments that were lit up green across the globe

1000s – followers who engaged with us on social media

Museum acknowledges our contribution to mitochondrial donation

The Science Museum in London is home to award-winning exhibitions, iconic objects and stories of incredible scientific achievement. It’s also now home to a display showcasing the history of mitochondrial donation and the role The Lily Foundation played in changing UK law.

Not only does our inclusion in the showcase raise the profile of our charity, it also acknowledges the important part we played in the legalisation of mitochondrial donation. We were representing the patient voice in parliament almost a decade ago, and we’re still advocating for patients today.



How people power is spreading the word

When his son Jude was diagnosed with mitochondrial disease, like so many other parents Dale had never heard of the condition. But since that day he’s made it his mission to spread the word about our work. It started with sponsoring his sons’ youth football club by putting Lily branding, rather than his company’s, on the shirts.

“We now sponsor 16 youth and three senior teams in various leagues, so that’s a lot of shirts. Redruth Ladies have just won promotion, and they’ve been massive supporters... Plus, it’s made people visit the website and research mitochondrial disease more as soon as they hear about it.”

Dale is driven by an intense longing to help in any way he can. He also believes making personal connections is a great way to get people involved, so he’s made a point of taking Jude to meet all the football teams.

“There’s nothing we can do physically apart from keep Jude comfortable, but what we can do is spread the word to generate more interest in the disease, more research and more money for the Foundation. There has to be hope, that’s what keeps you going. It’s in the Lily logo, isn’t it? I promote that logo wherever I can. I’ve even got it on the spare wheel of my Land Rover.”



We couldn't do this without you

Thanks to your generosity, our income this year from gifts, grants and donations totalled £1,180,754

A few of the highlights:

58 Fundraising Teams came together to raise more than **£207,000**

London Marathon - **£127,000**
44 runners including Lily Operations Manager Claire and Ben, our Chairman

Cinderella Gala Ball - **£64,000**

22 boxers raised over **£37,000** at Lily Fight Night

First ever South West Golf Day raised over **£12,000** and is now a staple in the Lily calendar

A fundraising journey through mito

Faced with the hopelessness of his young son Bill's mitochondrial disease diagnosis, Sid found purpose through fundraising. Aiming to raise both money and awareness, he turned his passion for running into a mission, beginning by completing two marathons in a week!

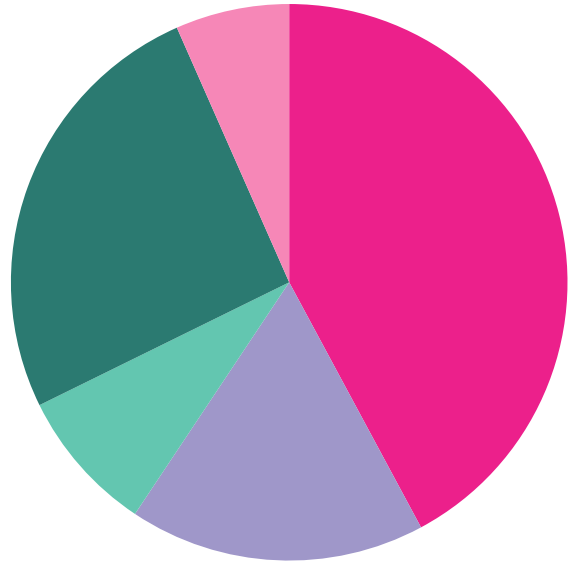
"You feel so helpless when you get the diagnosis and you're told there's no effective treatments or cure. But there's ongoing research, so you just want to put money in that pot. I'm motivated by the fundraising now and that keeps me mentally and physically fit. It's also good preparation for what's ahead of us."

Sid quickly hit a significant fundraising target, and that success has led to a series of ever-more ambitious events, inspiring friends, family and even the local community to get involved. His goal is to raise £100,000 to support mitochondrial disease research.

"We've been on the radio, we've been in the press, probably too many times. Bill and I are in the local paper almost every week! But by spreading the word about the disease, we're helping to raise awareness and that's just as important as raising funds."

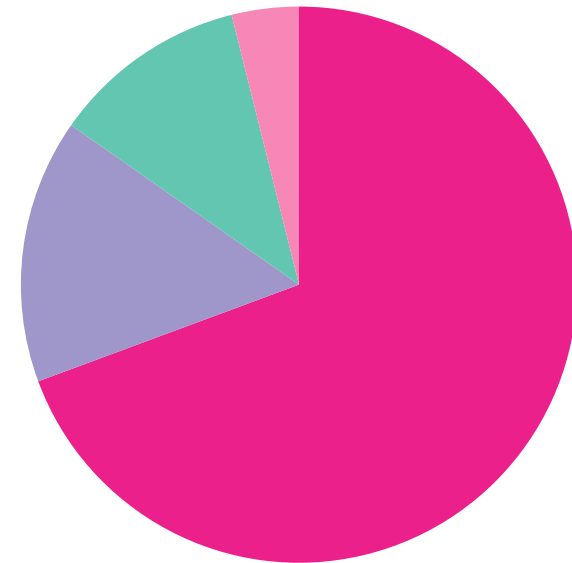


Income and expenditure Summary



- Voluntary income & donations (£411k)
- Lily fundraising (£168k)
- Grants (£82k)
- Sports events (£250k)
- Sundry (£64k)

Total income - £974k



- Charitable expenditure (£987k)
- Fundraising trading costs (£219k)
- Generating voluntary income (£162k)
- Governance costs (£56k)

Total expenditure - £1,424k

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.

Amy's story

Diagnosed with mitochondrial disease as a child after years of unexplained symptoms, Amy faced isolation, fear and uncertainty about her future. But attending a Lily Foundation Patient Information Day changed everything.

“Everyone was just like me. It felt really positive and upbeat, and I remember getting a good feeling about it – and that doesn’t happen often! Liz was telling us about future projects. When you’re diagnosed with mitochondrial disease, there isn’t much talk of the future. And the fact that the logo colours were pink and purple swayed me!”

For the first time, she connected with others who shared her experiences, finding hope, understanding and a sense of belonging. Today, Amy plays an active part in the Lily community, regularly joining the virtual coffee morning and even zip-lining at the Young Adult Support Weekend.

“The Lily Foundation... are a breath of fresh air and have brought so many amazing people into my life. The incredible friends that I have made all with a similar story to myself. I can ask questions and get answers. The Lily Foundation have become such a special part of my life.”



Thank you, Lily!





Looking ahead to next year

As we enter Lily's milestone 18th year, we're excited to build on our achievements with a series of impactful events and campaigns that celebrate this landmark anniversary. Our marcomms strategy will weave this theme throughout the year, creating opportunities to engage and inspire our supporters like never before.

We'll have a host of exciting new fundraisers beginning with a Lily skydive aiming to raise £10,000. We're also considering an Isle of Wight cycle challenge, an ambitious new initiative which promises to rally cycling enthusiasts and expand our reach.

On the research front, 2025 will see the relaunch of Lily's PPI group under its new name, IMPACT, as it takes on a pivotal role in the innovative LifeArc TREAT MITO Centre. This transformation reflects our commitment to amplifying the patient voice and driving forward ground-breaking mitochondrial disease treatments.

Finally, we're thrilled to be hosting a prestigious 'Unlocking the future for mito' networking event in London, providing vital support for our fundraising efforts whilst building awareness of our cause among influential donors.

These events and initiatives, alongside the support of people like you, will ensure 2025 is a year of celebration, growth and progress for The Lily Foundation.



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.



31 WARREN PARK, WARLINGHAM, SURREY, CR6 9LD

thelilyfoundation.org.uk

Charity No: 1122071 Company No: 06400879

