



## What we've achieved

Since 2007 we've been navigating the complexities of mito, and so far we have:

Raised over £11 million

Invested in 23 research projects

Partnered with the UK's top mito research centres

Funded 2 groundbreaking diagnostics projects

Changed the law on mitochondrial donation

Launched our Mito Patient Advisory Committee

Supported over 1300 families affected by mito

Donated £200,000 for care equipment and respite breaks

Hosted annual meet-ups and events for our families

With your help we can keep spreading the word about mito, supporting those affected by it and working tirelessly towards finding treatments and that elusive cure.

## Our mission

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.

Every other day a baby is born in the UK who may develop Serious mitochondrial disease.

But there is hope.  
There is The Lily Foundation.



## Make a difference

### Make a donation

It's easy to give through our JustGiving page



### EasyFundraising

Raise funds for us simply by doing your online shopping.



### Check out our shop

Visit our website to shop for Lily gear and gifts to support and raise awareness at the same time!

### Payroll Giving

Payroll Giving is simple to join and tax-free, meaning that if you make a donation of £10, only £8 will come out of your salary and the taxman pays the difference! Find out more at [thelilyfoundation.org.uk/payroll-giving/](http://thelilyfoundation.org.uk/payroll-giving/)

# The Lily Foundation

Fighting mito,  
finding hope.

**thelilyfoundation.org.uk**  
**0300 400 1234**





## How our journey began

Hello,

My name is Liz and our journey with mitochondrial disease began in October 2006 when our daughter Lily was diagnosed with the condition.

We searched for support and information about the disease but found none. We felt shocked, devastated and alone.

In 2007, after we lost Lily, we set up The Lily Foundation to ensure that no other parents ever had to tread such an isolated path as we did.

To get in touch with me, please email [liz@thelilyfoundation.org.uk](mailto:liz@thelilyfoundation.org.uk).

**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.**

## What is mitochondrial disease?

Mitochondrial disease, or mito, is a genetic condition that prevents cells in the body from producing enough energy to survive. It can affect any part of the body, such as the heart, brain, muscles, eyes, hearing, stomach or kidneys.

It's a debilitating disease that can cause devastating symptoms including poor growth, muscle weakness and pain, seizures, vision and/or hearing loss, gastrointestinal issues, learning disabilities and organ failure.

**When Charlie was first diagnosed we were given a leaflet about The Lily Foundation, and told it was a great charity to go to for support.**

**Sure enough, Lily was there for us from day one, providing emotional support, information, practical guidance and even helping fund a hydrotherapy pool to help Charlie's mobility.**

- Anna



## Mitochondrial disease isn't as rare as you think



**Mitochondrial dysfunction has been linked to diseases including dementia, Parkinson's, epilepsy and cancer.**

Every other day in the UK, a baby is born who may develop serious mitochondrial disease. There are currently no effective treatments, and no cure, for this complex and life-limiting disease.

Mitochondrial dysfunction has been identified as a key factor in other, more common, diseases including dementia, Parkinson's, epilepsy and cancer. So the research studies and clinical trials we fund stand to benefit not only those with mito, but potentially millions of others too.

That's why, despite being a little-known disease, mito could be the key to one of the most important medical breakthroughs of our time.

## Get involved

There are lots of different ways you can get involved with us, either as an individual or through your employer, to help raise funds and awareness to fight mito.

- Enter one of our charity events.
- Hold a fundraising event of your own.
- Attend or sponsor a Lily event.
- Make a one-off charitable donation.
- Volunteer for us.
- Make The Lily Foundation your charity of the year.
- Give an in-kind donation (including pro-bono work).
- Fund a project or one of our services.
- Give as you earn.

Sign up to our newsletter for all the latest news, events, personal stories and lots more.

[thelilyfoundation.org.uk](http://thelilyfoundation.org.uk)

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Charity No: 1122071 Company No: 06400879