



Fighting mito, finding hope.

Have you heard of The Lily Foundation? We're the UK's leading mitochondrial disease charity, and the largest charitable funder of mitochondrial research in Europe.

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.

Mitochondrial disease, or mito, is a rare genetic disorder that affects people in very different ways. It often affects babies and young children, and the long-term prognosis for sufferers is poor. There are currently very few effective treatments, and no cure, for this complex and life-limiting condition.

The 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 available 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 quickly grew into a national charity which today supports over 1200 families. Run by a small team of dedicated staff backed by a medical board drawn from the UK's top centres for mitochondrial research, The Lily Foundation forms a vital link between patients, doctors and medical science bodies.

Since 2007 we have:

- Raised over £9.8 million.
- Invested in 20 ground-breaking research projects in the UK and overseas.
- Partnered with the UK's top mitochondrial research centres.
- Helped develop and launch two mitochondrial genetic testing programmes.
- Changed the law on mitochondrial donation.
- Launched our UK Mito Patient Registry.
- Supported over 1200 families affected by mito.
- Offered patients respite breaks and help with specialist care equipment.
- Hosted annual meet-ups and events for our patients and families.

Together we're navigating the complexities of mitochondrial disease: today raising awareness 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 in the UK a baby is born who may develop serious mitochondrial disease. But there is hope – there is The Lily Foundation. Help us make a difference.

thelilyfoundation.org.uk

