

Does someone you love have mito?

# Fighting mito, finding hope.

#### We're here for you

Being diagnosed with mitochondrial disease can be frightening and upsetting, but also very lonely. Because mito is so rare, it's hard to find people in the same situation, and that's why The Lily Foundation exists. Here are some of the ways we provide ongoing support.

#### Lily Family Weekend

A unique opportunity for families to get together and relax, with social activities, informative talks and workshops from mito experts for adults and plenty of fun for the little ones.

#### **Patient Information Days**

Come and meet us at these informal yet informative occasions hosted by the specialist mitochondrial clinics in Newcastle, Oxford and London.

#### Private Facebook group

Our private Facebook group for families affected by mito is somewhere you can connect with others who understand your situation, share experiences and make friends.

#### Virtual coffee mornings

Patients and family members from all over the country come together over Zoom for these informal weekly meetings, a great way to feel less isolated and better informed about mito.

#### The latest news, support and registries

We're committed to funding research to learn more about mito and improve the lives of patients. Sign up to our newsletter via our website and we'll keep you up to date with the latest research and clinical trials, plus news about Lily events, campaigns, personal stories and more. If you'd like to create an account with us and become part of our registry, please scan the QR code overleaf to start your Lily journey.

#### Access to medical registries

Registries like our UK Mito Patient Registry are a great way for patients to share details of their condition to improve care, guide research and help develop new treatments.

#### Lily Wish Fund

A grant scheme designed for patients to access something to improve their lives, such as specialist equipment, a home or garden adaptation or even a short break. Visit thelilyfoundation.org.uk/lily-wish-fund to apply.

#### Benefits advice

We'll take the stress out of understanding what benefits you might be entitled to and applying for those benefits.

#### Just need someone to talk to?

Everyone's mito journey is different, and every person living with the condition faces their own challenges. But help is available – whether it's a specific question, a reassuring chat or some emotional support, we're here to listen.



The Lily Foundation offers us a safe place to meet other families in the same boat as us, they offer us understanding, love and support. Although our daughter is no longer with us our son is a non-affected carrier. The Lily Foundation offers us hope that one day a cure will be found.



## You're not alone

#### Join our Family Facebook Support Group:

Search Facebook for "The Lily Family Mito Support Group" and request to join.

#### Find information online:

Visit thelilyfoundation.org.uk and mitochondrialdisease.nhs.uk.

#### Join our database:

Scan the QR code to create an account on our website and begin your Lily journey.

### Talk confidentially:

Call Liz on 07947 257247 or email liz@thelilyfoundation.org.uk.

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