Fighting mito, finding hope.

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How the UK Mito Patient Registry uses your data

What happens to my data?

The Lily Foundation is committed to protecting any personal information that we hold. Any data you provide will be stored on a secure server to which only specially appointed staff have access.

De-identified (anonymous) data will be used to improve treatments and care within the field of mitochondrial disease. We will never share identifiable data or contact details with third parties without your express permission.

Personal data you submit online is encrypted in transit, so that it cannot be intercepted. Identifiable data is never passed to third parties or used for marketing purposes.

We fully recognise our obligations to meet the requirements of GDPR and you can find more details in our Privacy policy.

At all times your data remains your property, and you have the right to withdraw it from the registry at any time by emailing claire@thelilyfoundation.org.uk.

What about clinical trials?

There are an increasing number of clinical trials emerging for mitochondrial disease with many promising treatment advancements on the horizon. The Lily Foundation wants to ensure our UK patients get the earliest possible access to innovative trials that could delay progression and reduce debilitating symptoms.

Registries play a key part in identifying patients to take part in trials. They can help companies developing trials for mitochondrial diseases in three main areas:

- Firstly, the patient voice is now a vital component of trial design and patients' experiences and input can ensure that trials are designed in a way that is manageable for mito patients.

- Secondly, when companies are planning a trial, they can use the registries to find out statistical data about the numbers of patients who might meet the criteria for that trial. This helps them decide on the number of countries and the number of centres in each country they need in order to make sure they can recruit sufficient patients quickly enough.

- Thirdly, when they come to recruit patients for the trial, they can ask the registries to contact all potentially eligible patients on their behalf. This is helpful because usually only one or two centres in every country will be running the trial. As those centres only know the patients who are regularly seen by them, patients elsewhere in the country may miss out without the involvement of the registries. Also, if pharmaceutical companies find that recruitment into their particular clinical trial is going slowly, they can use registries to help them recruit their remaining patients. This can speed up the recruitment of participants, meaning that a trial can start more quickly.

How will I be contacted about clinical trials?

The registry helps speed up the process of clinical trials and patient studies by making it easier for drug companies to recruit patients.

In terms of identifying patients for clinical trials, the registry acts as a 'trusted intermediary'.

Only companies or researchers who undergo a rigorous ethical approval process can use the registry. Once approved, they can use it to request a specific patient group (for example, they can say that they are looking for adult patients with a particular gene mutation and symptom) for their trial.

If our registry committee approves the request, patients who meet the criteria are then contacted with details about the trial and how they can take part. Patients are then free to decide whether or not to contact the clinic running the trial.

Personal details of patients are never given to the company submitting the request.

What if I don't want to take part in clinical trials?

Only patients who opt in will be contacted about clinical trials and studies. You can change your opt-in status at any time. Even if you don't want to be involved in trials, your disease experiences can still help to shape the support services available to the wider mito community.