



E P I C



Expert Patient Input Committee

Research is the key to finding treatments and an eventual cure for mitochondrial disease, and we believe the real experts are the people living with the disease – you. You're the fighters, you're the mito heroes – and this is your chance to be part of something EPIC.

what is EPIC?

EPIC stands for Expert Patient Input Committee. It's an online, virtual committee made up of people who are affected by mitochondrial diseases and who are willing to share their experiences to help shape research, clinical care and treatments.

It's important to know that being part of EPIC is not the same as taking part in research. It's not about taking part in a trial or study to test a new treatment or care option.

Why is it important to have an Expert Patient Input Committee?

We believe that people who live with mitochondrial diseases are the experts in their condition.

By sharing your experiences and insights, you can help researchers understand what's really important to people and families living with mito.

Your knowledge, which comes from lived experience, can help to fill in the gaps for researchers.

As a member of the mito community, you're in a position to share your unique insights and experiences which researchers may not have considered, and which have the power to change their thinking.

what are the benefits of being part of EPIC?

Having your say in research can be thought-provoking and inspiring.

It can be empowering to know that you're making a difference and helping to shape care and research for those affected by mito in the future.

It can open up new experiences and opportunities, where you can stretch yourself, learn new skills and feel part of a team.

You can work in a way that suits you, choosing projects that you're interested in and that best use your skills and knowledge.



Some of the exciting opportunities EPIC could offer you:

- Share your experiences of mito care and identify new areas for research.
- Learn about new research studies and decide if these are relevant, well-planned and of benefit to people with mito.
- Be the first to test new medical registries or clinical databases.
- Give feedback on new research tools, such as patient questionnaires.
- Develop patient leaflets and information sheets to make sure these are suitable for patients.
- Be part of a focus group into a particular aspect of your mito journey, such as your experiences of diagnosis.
- Take part in interviews about the realities of living with mito.



Who can take part?

Anyone with a confirmed diagnosis of mitochondrial disease, parents or carers, and those who have lost a loved one to the disease.

How do I take part?

You can sign up via our Lily medical registry. You'll then receive an email every time a potential project becomes available, with details of the project and what it involves.

How much time does it take?

It's up to you how much time you commit to EPIC. You only need to select the projects you're most interested in. Being part of EPIC is completely voluntary and you can always change your mind if you decide it's not for you. If you'd like more information or have any questions, please contact katie@thelilyfoundation.org.uk or call 0300 400 1234.



thelilyfoundation.org.uk

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