IMPACT

A Practical Guide to PPI

Patients, parents & caregivers

thelilyfoundation.org.uk

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Introduction

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 make an IMPACT in the world of mito Research.

What is IMPACT?

IMPACT (previously known as EPIC) is our Mitochondrial Patient Advisory Committee. It's a UK-wide, 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.

Why is it important to have a mito Patient Advisory 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 is not covered by IMPACT?

It's important to know that being part of IMPACT is not the same as taking part in research. It's not intended to increase your chances of being recruited for a trial or study to test a new treatment or care option. If you are interested in becoming a research participant, take a look at our 'UK Trials and Research studies' webpage for all of the research studies currently recruiting patients. Alternatively, head to our Patient Engagement webpages to learn more about the differences between Participation, Involvement and Engagement.

IMPACT is also not a forum to ask for personal or medical advice from the researchers. We ask that patients, parents and carers follow the usual channels for support offered by The Lily Foundation or, in the case of medical queries, refer directly to their mito care team.

What are the benefits of being part of IMPACT?

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.

> "I thoroughly enjoyed it and found it extremely interesting and informative. I came away from it feeling very hopeful and excited. The experience of being involved in a discussion with people who are so passionate and genuinely care about the future of people living with mito makes me really happy. It was presented extremely well, ensuring everyone was able to understand, and was listened to and valued. It was also great to meet other patients. All in all, a very fulfilling experience so far for me."

Some of the opportunities do allow the opportunity for you to be reimbursed for your time; however, please note that this is not the case for every involvement opportunity so should not be the principle reason to sign up to IMPACT. We are also happy to provide certificates as evidence of involvement in IMPACT work, if this would be of benefit to committee members (for example, for young people as evidence of extracurricular activities).

Getting Involved

What sort of things can I get involved in?

Here are just some of the exciting opportunities IMPACT 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-designed and of benefit to people with mito.
- Be the first to test new medical registries or clinical databases.
- Help to design and 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 small group discussions about the realities of living with mito.

> “It felt good to be part of something that is going to benefit those with mitochondrial Disease. It's nice to feel like people are working on the issues that affect our lives so much and nice to be able think I might be helping other people in the future too.”

Who can be involved?

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

How much time does it take?

It's up to you how much time you commit to IMPACT. We understand that managing a diagnosis of mitochondrial Disease is tough enough, so we want to make your involvement as flexible as possible. You only need to select the projects you're most interested in; however, we would ask that if signing up to IMPACT, you commit to a minimum of signing up to least 1 patient involvement project per year.
Because we rely on researchers to apply to IMPACT for patient involvement, it is possible that you may wait several weeks or months for an opportunity to come along, and then a couple may come along at once. All opportunities you may be eligible to be involved in will be shared via email, so please keep an eye on your inbox.

In addition, previous opportunities for patient involvement have always been very popular, meaning that we have often been oversubscribed when opportunities do come along. We strive to include as many diverse voices in research as possible, so if you aren't chosen for a particular opportunity you've signed up for, please don't give up as we will work hard to ensure you get a chance to be involved.

And, if you've taken part in a recent involvement opportunity, please be aware that priority for any future involvement opportunities may be given to other members of the committee who haven't yet had an opportunity to contribute.

Being part of IMPACT is completely voluntary and you can always change your mind if you decide it's not for you.

Do I need any particular knowledge or skills?

No – as long as you have lived experience of mitochondrial Disease then we want to hear from you! You will notice on our sign-up form that we ask some questions about whether you have a medical or science background, and we also ask about number of years affected by mito. This helps us ensure a diverse range of voices in our patient involvement opportunities but should not be seen as off-putting for those interested in signing up.

In addition, some involvement opportunities may require you to do some background reading to help prepare you for the sessions, or they may ask for you to do a task prior to an involvement opportunity. This helps to prepare you for the session so you can get maximum benefit and enjoyment from it.

Overall, we ask that people who join IMPACT bring with them a promise to be respectful of the researchers and each other. Whilst we understand that mitochondrial Disease can bring with it a multitude of challenges and frustrations, the purpose of IMPACT is to bring together patients, caregivers and professionals in a positive space where we listen to each other's perspective and benefits from the mutual sharing of knowledge and expertise.

Our vision is for IMPACT to be as diverse and inclusive as possible, so please let us know about any accessibility requirements or other adaptations that will make it easier for you to join us.

This all sounds great – how do I sign up?

You can sign up to join the committee by completing the online form on the Lily website. This short form is designed so that we can learn a little bit more about what motivates you to join the committee, and also helps us to match you to the most suitable involvement opportunities for you.

You'll then receive an email every time a potential project becomes available, with details of the project and what it involves.

More information or questions

If you'd like more information or have any questions, please don't hesitate to contact **katie@thelilyfoundation.org.uk** or call **0300 400 1234**.

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