

MitoNews Oxford

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Useful Contacts

Non-urgent email helpline for patients & professionals:
mitohelp@ouh.nhs.uk

Oxford Mitochondrial Centre

Administrator:

Sabrina Sturdy
01865 225899*

**Please note new number*

Family Care Advisors:

Adults:

heather.ryan@ouh.nhs.uk

Children:

rebecca.moore@ouh.nhs.uk

Physiotherapists:

jane.freebody@ouh.nhs.uk
katherine.browne@ouh.nhs.uk

Dietician:

judy.wadsworth@ouh.nhs.uk

Speech Therapist:

claire.blair@ouh.nhs.uk

Clinical Nurse Specialist:

sue.west@ouh.nhs.uk
07825 386230

Welfare Rights Officer:

eliza.riley@ouh.nhs.uk
07920 414075

Warmest regards to all of our MitoNews readers. We hope this newsletter finds you well.

We are delighted to have held two **Patient Focus Groups** in Oxford (via Microsoft Teams) and look forward to a third later this year. All members of the group attend the Oxford Mitochondrial Service, either as patients or relatives, and are helping to shape the delivery of your care in the future. This includes reviewing patient information leaflets and suggesting improvements to out-patient clinics. We are very grateful to those who have attended so far. If you're interested in taking part, please email mitohelp@ouh.nhs.uk

As the COVID vaccine rollout continues across the nation, we hope it all helps towards keeping everyone as safe as possible whilst restrictions begin to ease over the next month. If you have concerns over your clinic appointments - please be reassured that at the present time we will continue to offer patients video appointments, as well as face to face, as appropriate.

In the meantime we hope are enjoying the summer sunshine! Best wishes to you all.



Many congratulations to Liz Curtis, Founder and CEO of The Lily Foundation who was recently awarded an MBE in the Queen's Birthday Honours List, for the charity's work fighting mitochondrial disease.

Liz and her team do an amazing job supporting so many people living with Mitochondrial disease. You can read more about Lily and the support that is available on their website: www.thelilyfoundation.org.uk.

Useful websites

www.mitochondrialdisease.nhs.uk
www.mitochondria-newcastle.com

We're on Twitter!

Follow our twitter account at
[@ServiceOxford](https://twitter.com/ServiceOxford)

Meet the Team - Our Healthcare Assistant

Hello, my name is Emma. I have recently joined the Oxford Mitochondrial Service as a Healthcare Assistant. I moved to Oxford 4 years ago for university and I haven't left since! In my spare time, I like walking along the Thames river, drinking coffee and spending time with my Golden Labrador, Molly, who is a bundle of joy. I'm looking forward to hopefully meeting you one day, once everything is a bit more 'normal'!



Clinic Waiting Room

We apologise to our patients and families that we continue to be unable to provide magazines or toys in our clinic waiting room due to COVID infection control policies in the OUH Trust. However, we hope we will soon have a new TV monitor which should pass a few minutes of your time whilst waiting for your appointments!

The Lily Foundation have been kind enough to fund a TV monitor for our clinic waiting room, which is on order, and our team are working on useful information for you to look at!

Don't forget to bring your snacks and water bottles to clinic as we are conscious you spend a few hours there being seen by the multi-disciplinary team.

We are currently seeking support from local businesses to donate snacks and water bottles for our patients as we would like to have this available for you whilst waiting.

COVID Vaccine Feedback

The Mitochondrial Centres (Oxford, Newcastle and London) meet together regularly to share information and discuss significant issues. This includes the opportunity to report and share any information on any reported adverse reactions after the COVID vaccines for our patients.

There has been no evidence so far of any increased risk of adverse reactions from the COVID vaccine given to Mitochondrial patients.

It has shown there may be increased fatigue in patients but this is something that some mitochondrial patients do experience after other vaccines anyway. If you feel you have been very unwell after the COVID vaccine do drop us an email at mitohelp@ouh.nhs.uk describing your symptoms as it is helpful to collect this data.

Help Raise Awareness of Mitochondrial Disease in Mitochondrial Awareness Week

19th-25th September 2021

Keep a look out... every year, monuments around the world are lit up green to raise awareness for mitochondrial disease. We hope to be able to do an information stand in the John Radcliffe Hospital again this year - and listen out too as we may manage to get a little slot on local radio if we are lucky!

www.mitochondrialdiseaseweek.org