

MitoNews Oxford

Issue 11

Summer 2022

Useful Contacts

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Clinical Nurse Specialist
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Useful websites

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

Welcome to our Summer edition of MitoNews.

We hope you manage to enjoy some warm sunshine and perhaps dare to venture out for a holiday this year. We were so pleased that some of our Oxford Team (Those of us without Covid!) were able to attend the The Lily Foundation Family Weekend in July this year. Everyone was delighted to see familiar faces after all these years and enjoyed meeting those new to the weekend. As always it was a great event appreciated by many!

Do you have questions & concerns around the genetics of your mitochondrial disease?

How do I tell my children about their risk?

Can my relatives have genetic testing?

Are there family planning options available to me?

Are my children likely to inherit this?



Could my family members also be affected?

Our Principal Genetic Counsellor, Jo Lowndes, is available to help answer any concerns.
Email: mitohelp@ouh.nhs.uk

We're on Twitter!

Follow our Twitter account @ServiceOxford

**WORLD MITOCHONDRIAL DISEASE
AWARENESS WEEK**

19th—24th September 2022

Top Tips

Our Dietician, Rachel, gives us her top tips for staying hydrated...

Drinking enough fluids is vital for good health in the short and long term. Without sufficient fluids, early signs of dehydration you may notice include your body showing an increased thirst, a dry sticky mouth, stronger smelling urine, or less frequency of passing urine. Other effects may include worsening fatigue, poor focus, headaches, or feeling lightheaded or dizzy.

Individual factors, including age, warmer temperatures, humidity, exercise, or illness can all change the fluid amount our body requires, as they can speed up the evaporation of sweat on the skin or losses from the body. Individuals with more difficulties asking for drinks, understanding when they feel thirsty or accessing drinks themselves are more vulnerable to dehydration.

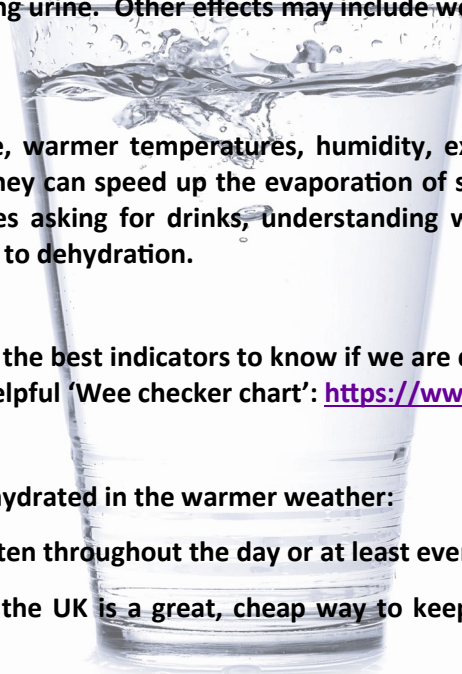
The colour of our urine is one of the best indicators to know if we are drinking enough, aiming for a straw or pale-yellow colour urine. Here is a helpful 'Wee checker chart': <https://www.eric.org.uk/wee-checker>

Here are some top tips to keep hydrated in the warmer weather:

- Aim for drinking little and often throughout the day or at least every meal and snack time if this helps.
- Drinking plain tap water in the UK is a great, cheap way to keep hydrated. Bottled water equally has the same hydrating benefits.
- Try some fun straws or colourful cups, ice cubes, shaped lolly moulds to make it interesting.
- Fluid-containing foods (such as watermelon, cucumber, melon, pineapple, pear, tomato, blueberries, oranges, yogurt pouches) contribute to fluid intake.
- Infuse your water (or ice cubes) with flavours by adding fruits (berries, cucumber, limes are favourites).
- Try a larger drink bottle. A great trick to drink more without thinking about it.

Tea and coffee provide water and can be a good way of keeping older adults well hydrated. It is helpful to be aware of caffeine intake, so opting for decaf options could be an option too.

Want to know more tips? Here are some great options for helping children to drink more: <https://www.eric.org.uk/blog/how-to-get-kids-to-drink-more-water>



Meet the Team

Our Consultant Clinical Scientist: Carl Fratter

Hello, I'm Carl and I've been part of the team since the service became fully established in the NHS back in 2007. You're unlikely to have met me though, as I'm part of the 'hidden' team in the laboratories trying to make genetic diagnoses, so potentially testing your blood, urine and/or muscle samples. My time working in genetic testing in the NHS dates back even further to 1997 when I finished university. Since then, I've been working as a Clinical Scientist in Oxford and I now lead the mitochondrial team in the lab. Outside of work, my daughter is now away studying at university, so my wife and I keep ourselves busy looking after our cats, chickens and fish! I enjoy playing tennis and squash, as well as running. Having completed a number of charity runs over the years, my next challenge is the London Marathon in October to raise money for the Lily Foundation; you can read more about that here: <https://www.justgiving.com/fundraising/carl4mito>

