

## What is Mitochondrial Disease?



Everyone has Mitochondria. These tiny packages of enzymes turn nutrients into energy for the body to grow and repair. They are the batteries that give energy for

the brain to work, the heart to beat and for just about every other bodily function you could think of.

- Mitochondria make-up 90% of the body's required energy.
- Mitochondrial failure leads to cell death. When many organ cells die, this is organ failure.
- Mitochondrial Disease can affect anybody, at any time, from new-borns to adults, though it is most commonly diagnosed in children.
- As a Disease, it does not differentiate between ethnicity, class, religion or age.
- At this time, there is no known cure. Research is vitally important and there are several key research organisations currently battling to find a cause and cure for Mitochondrial Diseases.

## Leigh Network

Leigh Network was founded by Faye Wylie in 2010, after she was diagnosed with Leigh Syndrome, a Mitochondrial Disease. This is a debilitating illness that affects Faye's energy levels and causes health problems such as dystonia (muscle spasms and tremors), vision impairment, headaches, speech and swallowing difficulties, and declining mobility.

Faye is, however, one of the fortunate ones. Mitochondrial Diseases can be fatal to young sufferers.



At the time of diagnosis, Faye's family realised that there was little support for those affected by Mitochondrial Disease.

*Faye*

After studying counselling skills, Faye decided to start her own organisation, bringing together those affected by these diseases, to share information and support each other. Leigh Network was born!

Now in it's 6th year, Leigh Network has grown to support families all over the UK who are affected by Mitochondrial Disease. Faye also uses Leigh Network to raise awareness of these conditions through the media and via fundraising for Mitochondrial research.

## Leigh Network Events

Faye realised that people affected by Mitochondrial Disease would benefit from meeting in person, so the first Leigh Network meeting took place in Liverpool in 2010. Families attended from all over the UK, and a specialist doctor kindly gave a talk about Mitochondrial Disease.



This meeting was a great success and since then, we have had meetings all over the country, in places such as Birmingham, Cadbury World, Peterborough, Legoland and Tropical Wings Zoo (Essex). This is to give families from all over the country a chance to come and meet everyone... We look forward to the next meeting!

## Awards and Media

- In 2012 Faye won the LCD Award for Local Campaigner of the Year.
- In 2013 Faye was nominated for the Cheshire Woman of the Year Award.
- In 2014, Faye met Samantha Cameron at 10 Downing Street, thanks to LCD, when attending the Change 100 Campaign.
- In 2015, Faye received an Award from Wirral Met College for Mentoring.
- In 2016, Faye won the Henshaw's Award for Young Person of the Year.



In addition to these Awards, Faye has appeared in several articles including local newspapers, author blogs and charity newsletters. She is an

Access Champion for LCD (campaigning for better physical access for disabled people) and she collaborated with Frank Field, MP, to ensure cinemas provide Audio-Description for visually impaired people.

Faye is very proud of the growing success that Leigh Network has achieved & the fact that she has been able to use her skills to help others. Everyone involved in Leigh Network recognises the importance of raising awareness of Mitochondrial Disease to raise funding for research and Faye has genuine hope that one day a cure will be found!

## Get in touch!

To contact Faye, you can:



Email: [leighnetwork@hotmail.co.uk](mailto:leighnetwork@hotmail.co.uk)



Tweet: [Faye@LeighNetwork](https://twitter.com/Faye@LeighNetwork)



Add the 'Leigh Network' Facebook Page

Leigh Network would like to thank the following for their backing:

-Leonard Cheshire Disability (LCD)



-The Lily Foundation



-Newcastle Mitochondrial Research Team at Newcastle University



A massive THANK YOU to everyone who supports Leigh Network.

# LEIGH NETWORK

Bringing together families affected by Mitochondrial Diseases



Funding research through charitable meetings & events