

## PATIENTS PAVE THE WAY FOR LAW CHANGE

On September 1<sup>st</sup> 2014 MP Fiona Bruce (Conservative for Congleton Cheshire) called upon the Government to delay bringing forward regulations for mitochondrial replacement.

A backbench debate took place at the House of Commons and we are delighted to report that there was significant support for the treatment to prevent the transmission of mitochondrial DNA disease.

It was fantastic to hear MPs supporting the regulations, David Willets (Conservative for Havant) stating "I think that this is a great piece of British scientific advance. We should congratulate the scientists at Newcastle University who have been in the lead in the research. My view is that provided it meets stringent safety requirements this is something that should go ahead because it will alleviate the suffering of constituents whom we represent." However, there are still a number of MPs who are very opposed to this new IVF technique.

We would like to say a huge thank you to those of you who responded to our request to contact your local MP by letter or arranging a meeting. This had a very powerful effect during the debate. The personal stories shared by your local MP demonstrated the impact of mitochondrial disease in families and brought the debate to life.

The Wellcome Trust hosted a drop in session prior to the debate to raise awareness for MPs. Professor Turnbull, Scientist Dr Lyndsey Butterworth and Sister Catherine Feeney attended from Newcastle along with a group of patients including Claire Exton (above right) and Liz Curtis from the Lily Foundation.

Whilst we continue to strive to find new treatments and



a cure for Mitochondrial Disease these techniques could prevent the transmission of the disorder for some families. This offers hope for future generations and we are looking for your continued support.

We have learnt from our experience in Parliament that human stories make people sit up and listen, we would urge everyone to make contact with their MP, tell them your personal experience and ask them to support you in the next debate. We are waiting to hear the date for the full debate which we hope will be early next year and be the final vote for MPs to decide on whether these techniques should go ahead. For further information and updates please follow or have a look at our website Facebook and twitter pages.



# Feedback

## We are moving!

As of 6th January 2015 the mitochondrial clinic will move to a new location at the old Newcastle General Hospital site on a Tuesday afternoon. The facility is brand new and the clinic will be exclusively for mitochondrial patients with improved parking and a café on site. Previously allocated appointments will be changed for you and posted along with information and a map.

**We continuously strive to improve your service and look forward to seeing you in the New Year**



## MERRY CHRISTMAS AND HAPPY NEW YEAR

from all the staff at the Wellcome Trust Centre for Mitochondria Research

We would like to say a huge **THANK YOU!** for all of your support and fundraising over the last year. Thank you for all of the individual donations we received directly, and for the donations we have received via our just giving page. All of the money is put directly into funding research to find a cure for mitochondrial disease. For more information about some of our fantastic fundraisers please see our just giving page which can be found at:

<https://www.justgiving.com/mitoresearchfund>

## FLU VACCINE

All patients clinically affected by mitochondrial disease are advised to have the seasonal 'flu' vaccine, which should be offered by your GP. If you require any additional information, please let us know.

If you have a story you would like to share or have any feedback about this Mitonews please email :

[mitonews@ncl.ac.uk](mailto:mitonews@ncl.ac.uk)

### Useful contacts

#### Newcastle upon Tyne

Specialist Nurse Tel: 0191 2821740

Address: The Medical School, Newcastle University, NE2 4HH London

Specialist Nurse Tel: 0203 4488009

Address: 8-11 Queens Square, London, WC1N 3BG

#### Oxford

Clinical Genetics Research Nurse

Address: Churchill Hospital, Headington, Oxford, OX3 7LJ

### Websites

The Rare Mitochondrial Disease Service for Adults and Children:

[www.mitochondrialncg.nhs.uk](http://www.mitochondrialncg.nhs.uk)

Muscular Dystrophy Campaign

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

Treat NMD [www.treatnmd.eu](http://www.treatnmd.eu)

CLIMB [www.climb.org.uk](http://www.climb.org.uk)

We Move [www.wemove.org](http://www.wemove.org)

The Lily Foundation

[www.thelilyfoundation.org.uk](http://www.thelilyfoundation.org.uk)

The Ryan Stanford Appeal

[www.ryanstanfordappeal.org.uk](http://www.ryanstanfordappeal.org.uk)