Welcome
Welcome to the latest issue of MitoNews UK, our newsletter for patients with mitochondrial disease. In this edition we are delighted to announce the launch of our new website and will give you details on how to access this, we will tell you about the exciting announcement by the government which will radically impact the future care for patients with mitochondrial disease and also have details of our annual patient information day.

The Lily Foundation have created a bespoke educational animation to explain how vital Mitochondria are to sustain life, and also what happens when they go wrong. This video will be used nationally to help educate and raise awareness of Mitochondrial Disease. To watch the video please visit the website: www.thelilyfoundation.org.uk

If you no longer wish to receive MitoNews, or would prefer to receive it by email, please complete the enclosed slip and return it to Sister Catherine Feeney (Newcastle University)

Law change for pioneering IVF technique

On the 28th June this year, the Chief Medical Officer outlined support for a change in the law, which would allow an IVF technique to eliminate mitochondrial disease, to be used in patients. The techniques have been developed in human eggs by Professor Doug Turnbull and Professor Mary Herbert at Newcastle University.

Reacting to the announcement, Professor Turnbull, Director of the Wellcome Trust Centre for Mitochondrial Research at Newcastle University said: “I am delighted that the Government is moving forward with publishing draft regulations this year and a final version for debate in Parliament next year. This is excellent news for families with mitochondrial disease. This will give women who carry these diseased genes more reproductive choice and the opportunity to have children free of mitochondrial disease. I am very grateful to all those who have supported this work.”

Alison Murdoch, Professor of Reproductive Medicine at Newcastle University, part of the team which has developed the technique added: “This is great news for UK science and gives hope to women who just want a healthy baby. The UK government has made a moral decision. “The death of a baby is a parent’s worst nightmare. Our research is leading to a pioneering IVF technology to reduce that risk for mothers who have abnormal mitochondria. There is still more research to do, but this decision means that we could eventually be allowed to offer it as a treatment.”

To receive more information in relation to egg donation: please visit the website: www.ncl.ac.uk/eggdonate
Me and my husband Gareth have a 3 year old daughter Penny and we had a baby boy, Ted, in November 2012. He was perfect and brought us so much happiness, completing our little family. After a few months of newborn bliss we were devastated to find out that Ted had a mitochondrial disease. We all remained positive and spent our every moment with our wonderful baby boy when he was in and out of hospital but sadly we lost him when he was 5½ months. Our aim now is to focus on something positive by raising money for the Mitochondrial Research Fund and help to raise awareness of mitochondrial disease. On July 20th we held a vintage bake sale, it was a fantastic day and we raised £1005! We were completely amazed at how well we did and feel so overwhelmed at the amazing turnout and generosity of everyone! We hope that Newcastle University mitochondrial research fund is pleased with our fundraising. We are doing it in memory of our beautiful baby boy Ted and hope that we are making him proud!

We want to hear your news! If you have a story you would like to share or have any feedback about Issue 10 please email: mitonews@ncl.ac.uk