

Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update

On the 24th August 2013, **Gayle Purdie** and 4 friends took part in a challenge called Tough Mudder. Her impressive fundraising story is described in her own words below.



Tough Mudder events are hard-core 12 mile-long obstacle courses designed by the Special Forces to test your all around strength, stamina, mental grit, and camaraderie. It was one of the most difficult physical challenges I have ever taken part in, but the bonus was that I was raising money for Mitochondrial Research whilst doing it. The reason I compete in these mad events is for my amazing, wonderful and inspirational friend Susan and for everyone with Mitochondrial Disease. I hope that by raising money for Newcastle it will help their research and hopefully in the future a cure can be found. Myself and the rest of the guys have signed up to complete it again this year, on the 14th June 2014. I can't wait to compete in it again and raise more money for Mitochondrial Research and to help my amazing friend, Susan.

Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update ★ Fundraising Update

Patient Log books are now available please ask for yours in clinic.

Many thanks to those who have already responded to the consultation and contacted their local MP. Including Mr Roden who wrote to his MP. His MP has contacted the department of health on his behalf and is actively waiting to respond and the vote to be called. If anyone else has contacted their MP please get in touch with Mitonews and let us know your stories!

Copies of the October 2013 patient information day talks are now available on our website, which can be found at the following address www.newcastle-mitochondria.com. Alternatively DVDs are available, and can be requested from Sister Catherine Feeney by calling her on (0191) 2821740.

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

Julie Phipps, Clinical Genetics
Research Nurse

Email: Julie.Phipps@ouh.nhs.uk

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

Websites

The Rare Mitochondrial Disease Service
for Adults and Children:

<http://www.newcastle-mitochondria.com>

Muscular Dystrophy Campaign

www.muscular-dystrophy.org

Treat NMD www.treatnmd.eu

CLIMB www.climb.org.uk

We Move www.wemove.org

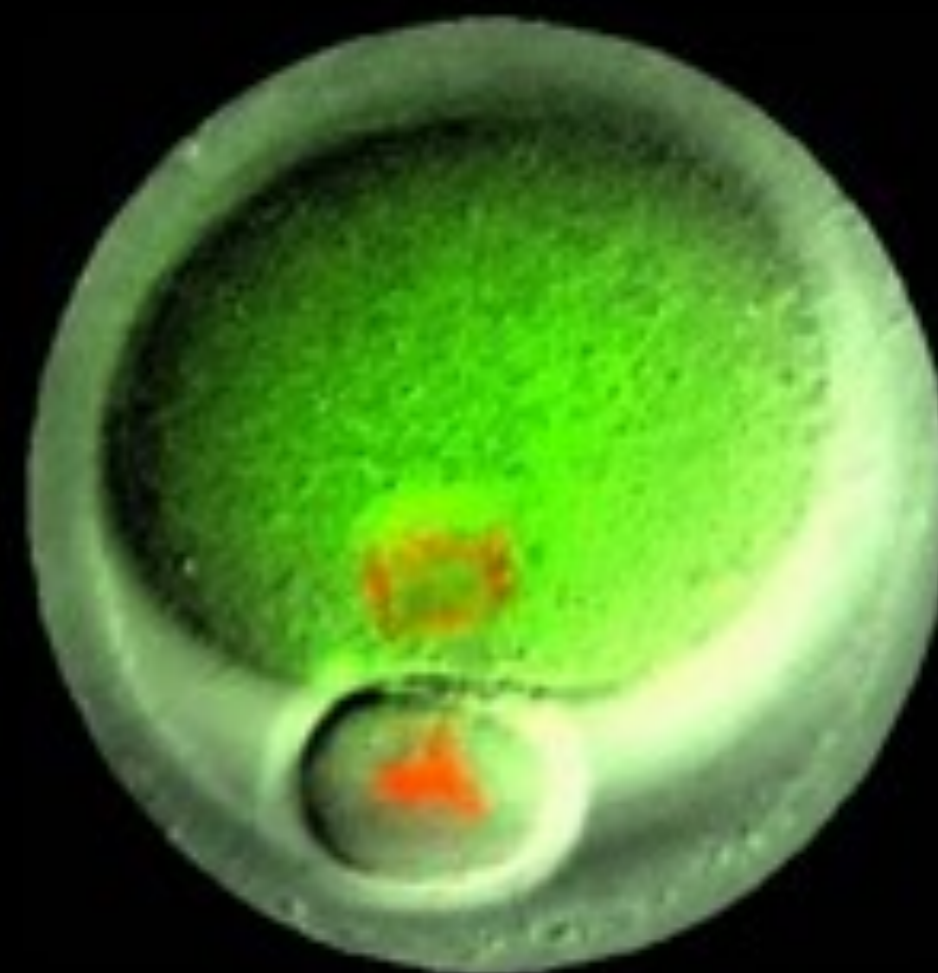
The Lily Foundation

www.thelilyfoundation.org.uk

The Ryan Stanford Appeal

www.ryanstanfordappeal.org.uk

MITOCHONDRIAL DONATION EDITION



In this issue:

- The science behind mitochondrial donation
- How you can get your views represented
- Fundraising update
- News and contact details

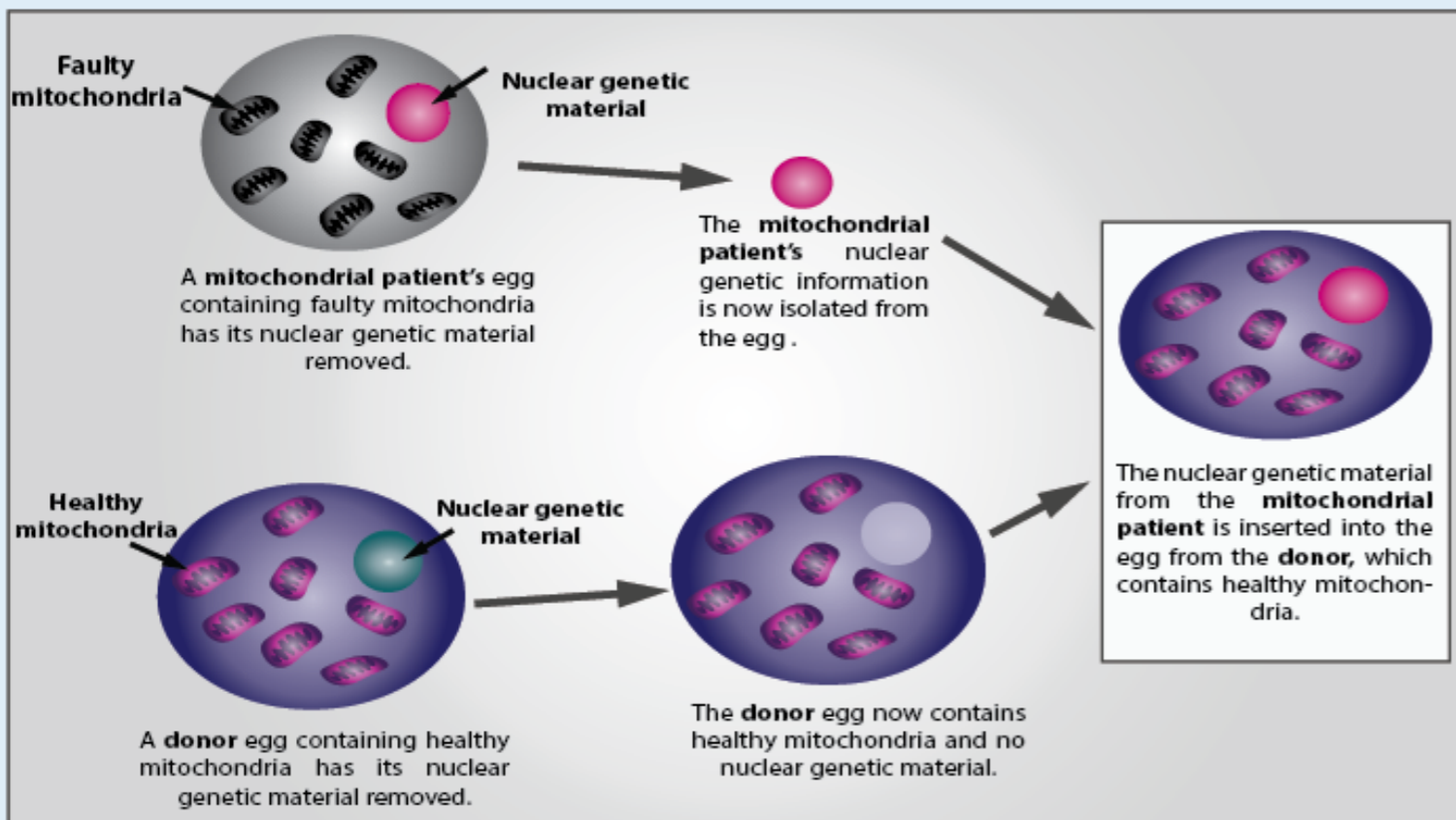
For updates, please like and follow us on Facebook or Twitter by searching for Mitoresearch.

Alternatively please get in touch with us at: mrg.socialmedia@newcastle.ac.uk

Have **your** say

The Government would like to find out what the public in the UK think about new specialist IVF techniques being developed by scientists at Newcastle University to prevent mitochondrial DNA disease. Here is your quick guide describing what it's about and how you can make sure your views are represented.

What is the science behind this new technique?



Will this technique alter the patient's nuclear DNA?

This technique will not alter the nuclear DNA but will allow a donor to donate healthy mitochondrial DNA to a patient with mitochondrial disease. The combination of healthy mitochondrial DNA from the donor and nuclear DNA from the patient will enable women who are affected by mitochondrial DNA disease to have children genetically related to them but free of mitochondrial disease. As the technique does not alter nuclear DNA, it will not alter a child's unique identifying features such as hair, eye, or skin colour.

99.9%

of genes are found within the nucleus. **None** of the mitochondrial genes that will be replaced by the donor mitochondrial DNA will contribute to personal characteristics such as eye colour and height.

Why respond?

The law currently does not allow this type of technique to be used in humans. The government would like the public's opinion about changing the law to allow these techniques to be used. This could allow specialist doctors to gain a license to perform this technique and offer it to mitochondrial patients who request it. It is important that, as patients, your views are represented and we would encourage **you, along with your family and friends**, to respond to this consultation. It is important that MP's understand the human side of mitochondrial disease.

How do I respond?

If you would like to have your views heard, and want to respond to the consultation directly, please go to the website highlighted below. As well as responding online to the consultation or instead (if you do not want to respond online), you could also follow one, or all of the suggestions on the right.

- Respond directly via the website below
- Discuss mitochondrial disease, your personal experiences and this new IVF technique with your local MP.
- Write a letter to your MP; to find out who your MP is please visit: <http://findyour-mp.parliament.uk>
- Write to Jane Ellison (Parliamentary Under-Secretary of State for Public Health). For her contact details please see : <http://www.janeellison.net/index/contact>

<https://www.gov.uk/government/consultations/serious-mitochondrial-disease-new-techniques-to-prevent-transmission>

Our response

If you log onto the website above, it will give you access to respond directly to the consultation. To help you understand what they are asking, and how we are responding, please see the answers below:

Question 1 refers to the removal of the nuclear genetic material from the patient and donor eggs as illustrated in the diagram on the page opposite, we agree with this definition.

Question 2 refers to the removal of nuclear DNA and we agree with this description, although we believe the restriction requires further discussion.

Question 3 describes the role the HFEA (Human Fertilisation and Embryology Authority) will play in regulating this technique. We agree that the HFEA should have this role. We also believe it is important at this stage to consider the regulation of access to the technique once it is established and becomes routine.

Question 4 refers to how the technique should be regulated. We agree that the HFEA should oversee the use of this technique, and that the HFEA should provide licenses to regulate its use. We hope that the long term regulation of this technique would not unnecessarily delay patient's access to it.

Question 5 asks for your opinion on how the donation of mitochondrial DNA should be viewed. We believe that donors who donate mitochondria for this technique should be considered in the same way as organ/tissue donors. They should not have the same status as those donating eggs for fertility treatment.

Question 6 and 7 asks what information should be available to a person born following mitochondrial donation, and what information should be provided by the donor. We believe that the information made available should be in line with that available to recipients of organ and tissue donation.

Question 8 refers to what information the donor should receive about children born from this technique. In principal we agree with this approach, although we wish to highlight that we do not believe the donors should have any parental rights.

Question 9 is one of the most important questions as it asks for your comments. This is your opportunity to give your views and personal experiences of mitochondrial disease.

This is only a guide, the Government want to hear **your** opinions. If you want to respond but do not want to answer all the questions you don't need to, you can answer as many or as few as you like. Question 9 is the most important question and is your opportunity to describe your experience of mitochondrial disease and your view on the technique. **The deadline for responding is the 21st of May.**