ALL PARTY PARLIAMENTARY GROUP ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS

on Rare, Genetic and Undiagnosed Conditions

An parliamentary drop-in on research into mitochondrial disease

Date: Wednesday 16 November
Time: 13:45-15:30

Parliamentarians in attendance:

Liz Twist MP
Mary Glindon MP
Siobhain McDonagh MP
Virendra Sharma MP
Chris Elmore MP
Andrew Lewer MP
Tom Randall MP
Anna Firth MP
Alan Brown MP
Feryal Clark MP
Mark Tami MP
Sharon Hodgson MP
Catherine West MP
Jessica Morden MP
Wera Hobhouse MP
Janet Daby MP
Grahame Morris MP
Stephen Doughty MP
Adam Afriyie MP
Jeff Smith MP
Marion Fellows MP

Summary

Liz Twist MP, chair of the APPG on Rare, Genetic and Undiagnosed Conditions, hosted an introductory information session for parliamentarians to raise awareness of the mitochondrial conditions and the importance of research. The APPG supported the delivery of the drop-in led by the Wellcome Centre for Mitochondrial Research at the University of Newcastle. The Lily Foundation attended the drop-in to share the work they do with people affected by mitochondrial conditions and the Wellcome Centre.

Key facts and figures

Mito is a subgroup of rare conditions. This means that there are less than 1 in 2000 people living with each mitochondrial condition. However, together, this group is very big. There are over 3.5 million people in the UK with a rare condition.

- 1 in 200 people carry a faulty gene which means that they can pass mito on to their children.
- Mito can be very serious and often fatal.
- The majority of mito conditions do not have a cure and rely on symptom management.
- Research into mito, and rare conditions more broadly, is significantly underfunded, having massive impacts on healthcare and other services.

The challenge

The lack of awareness of mito and the inherent rarity of the condition means that individuals in the community are often forgotten, especially in the development of wider policy.

While there are specialist centres for mito which provide a service to many in the community, there are still large groups of people living with mito that are lost under the integrated care systems and previously the clinical commissioning groups.

Many conditions do not have dedicated care pathways, they do not have NICE guidelines, they do not have support services, they have no treatment options.

Faults in mitochondria are the root cause of hundreds of other conditions, including cancer, Parkinson's, dementia, epilepsy and strokes. Research will therefore help develop in treatment for other conditions as well

Research into mito can improve treatment options and help achieve a faster diagnosis. This will improve the lives of people living with mito.

Showing parliamentarians how many people in their constituency are affected by mito

The Wellcome Centre for Mitochondrial Research developed an interactive tool which demonstrates the number of people in each constituency living with mito that are captured in the mito-cohort (the three specialist centres in the UK).

Please note that since these figures capture only people in the mito cohort, this number underestimates the population in each constituency with mito. It also doesn't capture those who have passed away from mito, nor the families affected.

The Team

Genetic Alliance UK
Genetic Alliance UK is the largest alliance of organisations supporting people with genetic, rare and undiagnosed conditions in the UK. Our 200+ members and the people they support are at the heart of everything we do. We advocate for fast and accurate diagnosis, good quality care and access to the best treatments. We actively support progress in research and engage with decision makers and the public about the challenges faced by our community.

Wellcome Centre for Mitochondrial Research
The Wellcome Centre for Mitochondrial Research is based within the Medical School of Newcastle University. A huge breadth of research is undertaken within our Centre to address questions regarding mitochondrial disease and dysfunction. Our aim is to transform the promise of scientific advances into revolutionary treatments that restore mitochondrial health.

The team also runs one of three specialist centres for mitochondrial disease. The centre based out of Newcastle serves people in the North of England, Wales and Scotland. These centres provide a multidisciplinary holistic approach to addressing mitochondrial disease.

The Lily Foundation
The Lily Foundation is the UK's leading mitochondrial disease charity and the largest charitable funder of mitochondrial research in Europe. Our mission is to improve the lives of people affected by mitochondrial diseases, while working towards a future where mitochondrial diseases can be effectively treated or cured.

We provide essential, ongoing support to patients, their families and designated carers. We educate, inform and raise public awareness about mitochondrial diseases. We fund scientific research into mitochondrial diseases in order to advance the search for effective treatments and cures.