



## ONLINE MEETING OF THE APPG ON MOTOR NEURONE DISEASE

10:30am–11.30am on Wednesday 1 December 2021

### Attendees

Andrew Lewer MBE MP	Ian Lavery MP (researcher)
Amanda Solloway MP	Jane Hunt MP
Barbara Keeley MP	Jason McCartney MP
Barry Sheerman MP (researcher)	Karin Smyth MP (researcher)
Brendan Clarke-Smith MP (researcher)	Marion Fellows MP
Cat Smith MP	Mark Tami MP
Claire Hanna MP (researcher)	Martyn Day MP
Chris Evans MP	Mary Robinson MP (researcher)
Christina Rees MP	Nia Griffith MP (researcher)
Christine Jardine MP	Nick Thomas-Symonds MP (researcher)
David Johnston OBE MP (researcher)	Richard Fuller MP
Duncan Baker MP (researcher)	Dame Rosie Winterton MP
Sir George Howarth MP	Stephen Crabb MP (researcher)
Gillian Keegan MP (researcher)*	Steve Baker MP
Hilary Benn MP	Stuart McDonald MP (researcher)
Ian Byrne MP	Toby Perkins MP (researcher)

*\*Represented in her role as constituency MP*

### Peers

Baroness Ilora Finlay

Lord Hector MacKenzie

### 1. Welcome and introductions

Andrew Lewer MBE MP welcomed everyone to the meeting to discuss targeted funding for MND research. He informed attendees that the meeting would be recorded, and the video placed on the APPG's webpage after the meeting.

Andrew updated attendees on the recent Government announcement that it is to invest £50 million in targeted MND research as part of a wider package of £375 million for research into neurodegenerative diseases over the next five years. He thanked the efforts of MND

charities, scientists and people living with MND who formed the United to End MND coalition.

Andrew paid tribute to former sportsmen living with MND, Rob Burrow, Doddie Weir and Stephen Darby, who have helped raise awareness of and support for the United to End MND campaign. He also thanked colleagues across the political spectrum for their support and emphasised the need to ensure the £50 million funding is delivered as soon as possible.

## **2. The impact targeted funding for MND research will have in the search for effective treatments and a cure – Professor Ammar Al-Chalabi, professor of Neurology and Complex Disease Genetics at King's College London**

MND research is well positioned to translate discovery science into treatments. Gene therapies are looking very promising; if you can cure a subset of people with MND then it may be possible to find a cure for other types of MND. This changes it from a hopeless condition to one where we know a cure is possible.

The targeted funding will enable scientists to work in a national and coordinated way and will pull together the research needed to accelerate the search for a cure. It will give every MND patient the opportunity to participate in a clinical trial whereas only 8% of patients can currently take part. Scientists will be able to learn from every patient in clinical trials which will help develop and test new treatments and improve understanding.

The UK has world-leading infrastructure: the largest population-based register of MND in the world; two out of the three major clinical trial platforms in the world (MND-SMART and TRICALS); pioneering remote technology for patient assessment; and leading biomarker scientists in the country. This work is powerful but is currently working independently. The funding will help coordinate this, so it works as a single harmonious unit.

With the funding, scientists will be able to build the new infrastructure they need. Currently, when new treatments are identified, they are tested in cells and each lab employs a different system for this testing. However, going forward, scientists will be able to create a national pipeline that combines the systems for testing and exchanging information. A single infrastructure like this can act as a single point for industry.

## **3. The future of MND research in the UK in collaboration with patients, researchers and clinicians – Thos Cochrane, Senior Medical Director at Biogen**

Thos explained that Biogen suffered a setback when researching late-stage asset intended to treat MND and therefore had to discontinue the programme due to lack of efficacy. However, Biogen remained committed to MND research and decided to pursue therapies for genetic subsets of MND. If in some of the subsets they understand the disease better, then the learning would lead to new approaches and therapies for people with MND.

Biogen currently have four investigational drugs for MND in clinical trials. Two of these are directed at genetic subsets of MND but the other two have the potential to be therapies for broad MND. There are also other assets in the pre-clinical stages, therefore Biogen are as committed as can be to the MND space.

Thos highlighted the importance of active collaboration between government, academic researchers and the pharmaceutical industry. Biogen rely on countless individual interactions with academic physicians – each of whom is working independently – and so it is labour intensive to find out who is working on what. However, if academic researchers are working together and pooling their resources, not only do they increase their chances of scientific success, but it also increases the likelihood that companies like Biogen are able to find and work in collaboration with them.

Later in the research process there is the need to better understand the natural history of MND and its genetic subsets. Particularly in the latter, published literature is inadequate and there is a large amount of unpublished data in the records of academic hospitals and in the NHS, records are robust but not accessible to researchers or pharmaceutical companies. If there is a coordinated effort to collect this data and share it appropriately it will save countless amounts of money and potentially years of effort because this data can improve study design, reduce trial duration and help answer questions that trials cannot answer. When it comes to MND every wasted month, every wasted year, is wasted lives.

#### **4. A personal perspective – Nicola Waters, MND patient representative**

Nicola is a former Civil Servant at the Department for Business, Energy and Industrial Strategy. She was diagnosed with MND in March 2019 and has been a leading figure in the United to End MND patient group.

On behalf of the MND patients' group, Nicola thanked Andrew Lewer MBE MP, the APPG on MND and parliamentarians for their role in helping to secure the £50 million investment from the Government.

Nicola explained that from the moment patients with MND are diagnosed, it is a hopeless situation. She has two sons aged seven and ten, and on every birthday and Christmas she wonders if it will be her last one. However, this outlook is now changing because of the Government's decision to fund targeted MND research. The MND community knows nothing is guaranteed, but this funding announcement offers them real hope.

Going forward, the focus for patients is supporting scientists and ensuring the £50 million is targeted at MND research and not other neurodegenerative diseases. It is also important to ensure the funding is awarded to the programme as a whole rather than making scientists to apply for multiple awards.

Given the rapidly progressing nature of MND, patients would like to see this rolled out as quickly as possible. The UK's leading neurologists have set out a detailed plan for the new MND research unit and now is the time to give them the tools to make this happen.

#### **5. Questions and discussion**

Geoff Burrow, father of former Leeds Rhinos player Rob Burrow with MND, thanked parliamentarians for their support for the United to End MND campaign. He asked MPs and Peers to push the Government to set out a roadmap for when and how the £50 million

funding will be made available. In response, Andrew Lewer MBE MP stated there are parliamentary mechanisms to push on this, including parliamentary questions and letters to Ministers.

Professor Al-Chalabi said the first tranche of money from the NIHR and MRC has been put together with money from a charity called LifeArc, the MND Association and the My Name's Doddie Foundation. This stands at £4 million and will kickstart the infrastructure and working group. The Business Secretary, Kwasi Kwarteng MP, has also said more detail on the £50 million investment will be made available by the end of January.

Steve Baker MP congratulated everyone on the success of the campaign and suggested applying for a parliamentary debate to celebrate the Government's commitment and raise questions about how we move things forward. Andrew said those debate forms are being filled in and he will ask colleagues from across the House to support the application.

Barbara Keeley MP said she supported the idea of a debate and asked how GPs are given the information they need when diagnosing a patient with MND. Professor Al-Chalabi stated that the MND Association has worked with the Royal College of Physicians to create a system of flags for GPs to know when to recognise MND and refer the patient.

Baroness Finlay asked whether there is anything the House of Lords can do around the Health and Care Bill to ensure that the specialist services can be developed, not leaving a loophole where patients are missed. Andrew advised that the MND Association will have their eye on the Bill and will be in touch.

Chris Evans MP said he found Nicola's presentation moving and hopes the targeted funding will accelerate the search for a cure. He would also like to add his name to any application for a debate. He asked what is being done to ensure people are getting an early diagnosis of MND. He also asked if there is any research taking place which looks at the link between elite sport athletes and MND.

In response, Professor Al-Chalabi said it takes on average a year between the first symptoms of MND and diagnosis. This is partly because it is not well recognised but also because it is a devastating condition with no effective treatment or cure, therefore medical professionals want to be absolutely sure before giving the diagnosis. However, the targeted funding will hopefully allow doctors to move away from a diagnosis of exclusion to a blood test with a bio marker for MND. This will make it much easier to diagnose MND. He also stated that some research has shown that people with a particular genetic background were more likely to develop MND if they also played heavy sports. However, this link may not be causal therefore research is ongoing.

David Setters, who is part of the MND patient group, said the United to End MND coalition have put together a set of principles underlying the running of the new entity to guide targeted MND research. He asked parliamentarians to ensure those principles are put in place to ensure the funding is spent in the right places. Andrew said those principles will be looked at.