ONLINE AGM OF THE APPG ON MOTOR NEURONE DISEASE

THURSDAY 25 FEBRUARY 2021

Present

Andrew Lewer MBE MP (Chairman)
Debbie Abrahams MP
Tonia Antoniazzi MP
Steve Baker MP
Clive Betts MP (researcher)
Ian Blackford MP (researcher)
Ian Byrne MP (researcher)
Dr Lisa Cameron MP
Dan Carden MP
David Davis MP (researcher)
Caroline Dinenage MP (researcher)
Dave Doogan MP
Allan Dorans MP
Jack Dromey MP (researcher)
Chris Evans MP
Tim Farron MP
Marion Fellows MP (researcher)
Katherine Fletcher MP
Richard Fuller MP
Margaret Greenwood MP
Nia Griffith MP
James Grundy MP
Darren Henry MP
Wera Hobhouse MP (researcher)
Jane Hunt MP
Christine Jardine MP (researcher)
Andrea Jenkyns MP
Dame Diana Johnson MP
Gillian Keegan MP (researcher)*
Barbara Keeley MP
Stephen Kinnock MP
Seema Malhotra MP
Scott Mann MP
Jerome Mayhew MP
Jason McCartney MP
Andrew Mitchell MP
Carol Monaghan MP
Penny Mordaunt MP
Jessica Morden MP
Caroline Nokes MP
Christina Rees MP
Barry Sheerman MP
Tommy Sheppard MP
James Sunderland MP
Mark Tami MP
Nick Thomas-Symonds MP (researcher)
Stephen Timms MP
Michael Tomlinson MP (researcher)
Liz Twist MP (researcher)
Dame Rosie Winterton MP

*Represented in her role as constituency MP

Peers
Baroness Finlay of Llandaff
Lord MacKenzie of Culkein
Baroness Masham of Ilton

In attendance
Dani Baird, living with MND
Dr Brian Dickie, MND Association
Professor Chris McDermott, University of Sheffield
Alison Railton – APPG Secretariat

1. Welcome and introductions

Andrew Lewer MBE MP welcomed everyone to the AGM and meeting to discuss MND research. Andrew informed attendees that the meeting would be recorded, and the video placed on the APPG's webpage after the meeting. In addition, photos would be taken throughout the meeting.

2. Election of Officers and appointment of secretariat

The following Officers were elected to the APPG:

Chair - Andrew Lewer MBE MP
Vice-Chairs - Brendan Clarke-Smith MP
- Chris Evans MP
- Christine Jardine MP
- Barbara Keeley MP
- Christina Rees MP
- Mark Tami MP
Treasurer - Rosie Duffield MP

The MND Association was re-appointed as the Secretariat to the Group.

3. MND Research

Brian Dickie, Director of Research Development, MND Association

Dr Dickie started by sharing some facts and figures about motor neurone disease (MND). MND is a neuro-degenerative disease that affects the motor nerves in the brain and spinal cord. It progresses rapidly in most case with a third of people dying within a year of diagnosis and half within two years. It is considered rare but up to one in 300 people will develop MND in their lifetime. This means that 200,000 of the current UK population will develop MND.

The MND Association has funded research for over 40 years and is the largest funder of MND research in the UK. The Association is currently funding 85 research projects at a cost of £14.6m. Most of the projects are based in the UK but the Association also funds research in France, Italy, Finland and Canada.

The Association plays a key role in fostering international collaboration and one of the ways it does so is organising the annual International Symposium on ALS/MND, which is the world's largest event on the disease. The most recent Symposium attracted delegates from 48 different countries.

Developing effective treatments for MND has been difficult – it is a highly complex disease - but the research community believes it is on the cusp of new discoveries. There has been exponential growth in international research activity over the last 10 years, primarily driven by genetic discoveries.

Currently charity funding for MND-specific research exceeds governmental funding and the MND Association is campaigning alongside the My Name'5 Doddie Foundation and MND Scotland to change that. The charities are calling for the Government to invest in a virtual MND Research Institute which would:

  - help develop the drug discovery pipeline
  - provide a platform and network for relevant clinical trials
  - develop a clinical research programme to ensure that as much as possible is being gained from each trial

Dr Dickie's slides are available on the APPG's website.

Questions and Answers

Baroness Finlay asked about the impact of devolution on MND research. Dr Dickie replied that collaboration already happens across boundaries and this would continue. Tim Farron MP asked what MPs could do to support the bid for a virtual MND Research Institute. Dr Dickie responded to say support would be needed from more than one government department and that colleagues at the Association would share information on this in due course. Chris Evans MP asked about an apparent link between elite athletes such as Doddie Weir and MND and if late diagnosis was still a problem for people with MND. Dr Dickie responded that there is a hypothesis that athleticism could be a 'grain of sand' that might tip the balance of the scales in favour of someone developing MND, but more research is needed. Early diagnosis remains a challenge but research in this area continues.

Debbie Abrahams MP asked what other ways there are to potentially screen people for MND as is the case for other conditions. Dr Dickie replied that gene testing, where there is a family history, can be offered for younger members of the family and pre-implantation determination IVF can be used to prevent the gene passing to future generations. James Grundy MP asked about the relationship between certain genes and the probability of developing MND. Dr Dickie replied that the 'penetrance' varies between genes and between mutations of each gene. The risk of developing MND is not absolute.

Professor Chris McDermott – Gene therapy in MND

Professor McDermott gave a presentation on the clinical trial he is leading at Sheffield University which is testing a treatment called Tofersen on patients with the SOD1 MND gene. His work is part of an international trial being run by Biogen.

Prof McDermott described the process where the SOD1 gene creates faulty proteins which cause problems in the nerves and can lead to MND. The aim of the clinical trial is to stop the faulty protein being produced. The trial involves a lumber puncture procedure where genetic material (Tofersen) is added to the spinal fluid. Tofersen mirrors the gene to seek out the protein, binds to it and ultimately stops its production.

The interim findings from the trial relate to small numbers and confirmatory stages are currently ongoing. Patients with MND in the trial have experienced a slowing of functional decline, breathing strength maintained and limbs remaining strong.

The SOD1 gene accounts for about 1% of all MND cases but it gives hope that MND could be a treatable disease if these results are confirmed. There are many reasons to be hopeful: gene therapies are showing promise; there have been advances in our understanding of the biology of MND; and trial design and execution are improving. An MND Research Institute would help to accelerate work towards effective treatments.

Professor McDermott's slides are available on the APPG's website.

Dani Baird – person living with MND and trial participant

Dani explained that she has been on the Tofersen trial for nearly four years. She comes from a large family and MND has caused terrible devastation. She is the 5th sibling to develop MND and the other four siblings have all sadly died from MND.

Dani lives in Essex and is a patient at King's College Hospital in London. She has been travelling to Sheffield every month to take part in the trial. Dani explained how she wanted to help with research in any way possible. She has now had over 50 lumber punctures. Dani said that although it hasn't cured or reversed her MND, it does seem to have stopped her progression. Dani said taking part in the trial has given her hope for her and her daughters. She hopes there will be more research so other people with MND can benefit.

Questions and Answers

Geoff Burrow (father of former rugby league player Rob Burrow, who is living with MND) asked about effective treatments for MND and how close we are to a cure. Prof McDermott replied that progress has been slow but there is a sense that there will be a change of pace as the biological understanding of the disease improves and compounds are discovered that impact on key pathways of the disease. Kevin Sinfield (Leeds Rhinos) thanked MPs for their support for people with MND and congratulated the coalition of charities campaigning for increased government funding for MND Research (United to End MND).

Diana Wilkinson (Ian Blackford MP's office) asked about the importance of early diagnosis and screening and whether Tofersen could be used to treat other forms of MND. Prof McDermott replied that Tofersen still needs to be confirmed for the SOD1 MND gene. A study called ATLAS has been initiated looking at asymptomatic gene carriers who will have their neurofilament levels monitored throughout life. If their neurofilament levels begin to change, there may be the opportunity to offer treatment with Tofersen.

4. DWP Terminal Illness Review and Scrap 6 Months Campaign

Andrew Lewer MP reminded attendees that the MND Association and Marie Curie's Scrap 6 Months campaign aimed to reform the way the benefits system treats people who are terminally ill. The campaign has received cross-party support and the Chairman thanked Members of the Group for their continued support.

In July 2019 the Department for Work and Pensions (DWP) announced a review but 19 months later there has been no announcement of the outcome. The hope had been that there would be an announcement in the March Budget, but that seems increasingly unlikely. Jessica Morden MP had brought an Adjournment Debate on the issue this week and updated the Group. In his response to the debate, the Minister Justin Tomlinson MP had reconfirmed the intention to reform the 6 months rule, but he failed to mention removing the three-year award duration limit. The Minister confirmed that the review had not been delayed by the Treasury as previously thought but there were issues to address by the Department of Health and Social Care. Ms Morden reported she has sought a meeting with the Minister to discuss this issue further.

Andrew Lewer MP thanked everyone for attending the meeting and the speakers for their contributions. The Group will be in touch with Members regarding the ask to Government for increased funding for MND research and on ensuring the DWP's terminal illness review is published as soon as possible.

Alison Railton, APPG Secretariat March 2021