



AGM OF THE APPG ON MOTOR NEURONE DISEASE

09:30-10.30 on Wednesday 29th March 2023

MPs Present:

Andrew Lewer MBE MP
Barbara Keeley MP
Christina Rees MP
Brenden Clarke-Smith MP
Nick Thomas-Symonds MP
Justin Madders MP
Liz Twist MP
Kieran Mullan MP
Martyn Day MP
David Duguid MP
Mark Tami MP
Peter Bottomley MP
Ian Byrne MP

Peers Present:

Baroness Finlay of Llandaff
Baroness Watkins of Tavistock
Baroness Thornton
Lord Selkirk of Douglas

Others:

Sophie Delamothe from DHSC
Charles Squire – representing Michael Tomlinson MP
Emma McLellan
MND Association- Secretariat

Apologies:

Lord Hunt
Marion Fellows MP
Andrew Gwynne MP
Baroness Fraser of Craigmaddie
Baroness Hollins
Baroness Walmsley
Lord Foulkes of Cumnock
Tim Farron MP

Tony Lloyd MP

1. Welcome and introductions

Andrew Lewer MBE MP welcomed colleagues to the meeting. He outlined he would proceed with the formalities of the AGM before inviting Professor Al-Chalabi to address the group, highlighting he had been pleased to be a Vice-Chair for the All-Party Group from 2017-2019, and Chair from 2020.

2. Election of Officers:

The following Officers were elected to the APPG:

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|-------------|---------------------------|
| Chair | - Andrew Lewer MBE MP |
| Vice-Chairs | - Barbara Keeley MP |
| | - Brendan Clarke-Smith MP |
| | - Christina Rees MP |
| | - Christine Jardine MP |
| | - Jessica Morden MP |
| | - Sir John Hayes MP |
| | - Mark Tami MP |
| | - Louie French MP |
| | - Mary Robinson MP |
| | - Ian Byrne MP |

The MND Association was re-appointed as the Secretariat to the Group. It was confirmed that the financial contribution to the APPG does not exceed the sum of £12,500.

3. Presentation by Professor Ammar Al-Chalabi on MND Research Institute & emerging new treatments

Professor Al-Chalabi outlined the MND research Institute is a national network set up to accelerate the search for a cure for MND which will look at what causes MND, to making clinical trials, to testing treatments. It's a scientific endeavour but largely driven and led by patients. He highlighted the Institute includes several charity partners, such as the MND Association, My Name's Doddie Foundation and MND Scotland.

Professor Al-Chalabi outlined those involved in the Institute had been lobbying the Government over its promise of £50 million for ring-fenced MND funding. Highlighted there had been some bumps in the road in accessing this funding since this announcement, but it now looks as if it's coming out in 3 phases.

The first million has come out already and supported the launch of the Institute and network of 6 institutions: Edinburgh, Liverpool, Sheffield, Oxford, University College London, and Kings. £28.5 million was then announced in phase 2 and researchers are currently bidding for that money. The remaining amount, Phase 3, was discussed at a ministerial round table with Steve Barclay this year.

Professor Al-Chalabi outlined there were two main themes in MND research:

- Firstly, what's happening the patient that's affecting their rate and progression rate. This doesn't necessarily tell you how to treat the disease, but researchers need something that tells us why it's the disease is being perpetuated.
- Secondly, ensuring a national network is built to test potential new therapies in a standardized way. All the different methods have different outcomes, so there is a need to ensure answers are bring arrived at in the same way.

He outlined that researchers have put together something called 'Experts ALS' which is a trial system to do experimental therapies in humans. Currently, most therapies are tested in mice, but researchers want to test new therapies in people with MND. This will help them determine when a drug looks promising, and when it should be taken to a proper phase 3 trial.

Researchers therefore want a central place to collect all the information that's being discovered so everyone can access it and it's collected in a uniform manner.

Professor Al-Chalabi outlined there are many places in the UK that run centres for MND. However, whilst there are 22 MND Care and research centres, not all are research active, in fact some are 100% NHS. So, if one of those non-academic centres want to do a clinical trial, the only way for that to happen is for someone to buy out some of their time and provide another member of staff to support.

He highlighted that whilst most people with MND want to be on trials, the challenge is in ensuring they are accessible. Until two years ago, researchers had less than 1 trial a year to offer people, whereas now, there are 6 that can be offered. But serious work needs to be done on the co-ordination between research institutions and ensuring there is an even spread around the UK. Professor Al-Chalabi discussed some of the main challenges involved fair opportunities and involvement for all parties, e.g. how do researchers make sure things are equitable to everyone, and for everyone to feel involved and in control.

He outlined that phase 1 is well under way, and the Institute has had its collaboration agreement signed up to by all parties now, with the official launch happening later this year. The Institute now has a website, logo and comms plan set up.

4. Questions

In response to a question on different healthcare systems in different nations causing challenges for collaboration Professor Al-Chalabi outlined this is a problem, but can also provide opportunity, for example, there are networks across the UK but not in Scotland. Scotland is also resourced in a different well, for example they have far more MND nurses than the rest of the country, and their MND register is incredibly detailed, which is something he outlined we should learn from.

In response to a question about what is LifeArc, Professor Al-Chalabi outlined LifeArc is a spinout from medical research council technology unit. They have IP rights for 2 drugs for MS, so they have a lot of funds from that trust so they're very supportive for MND.

5. Emerging treatments

Professor Al-Chalabi then moved on to present information on three new emerging treatments for MND.

The first – is called AMX0035 – which is a repurposed drug. He outlined this is a commercial trial, where once a day you take a tablet. The results for this are mixed.

The second – is called Tofersen – it is a genetic therapy, a new technology. The results for this seem to be promising.

The third is - Interleukin 2 (IL-2,) which modulates the immune system. It's a self-injection, 5 days every 4 weeks. What researchers are discovering is that the important thing is that in the blood of people with MND, their immune system must not be too aggressive or too passive.

6. Questions:

On a question about the ethics of using placebos in these trials, Professor Al-Chalabi outlined that whilst it is difficult, it is essential, and actually, unethical not to use a placebo. The reason placebo randomised trials exist, is because as seen from trials in the 1950s for heart disease tablets, if everyone gets the drug, because they want it to work, everyone will all report improvement, regardless of what they're really experiencing. He outlined that whilst it was ethically difficult, there were lots of ways to mitigate that. E.g., one way is to not randomise 50/50, meaning you double the chance of people get the active. Or make it a shorter time for people to be on the placebo, e.g. for only 6 months.

In regards to a question on the restrictions around genetic testing Professor Al-Chalabi outlined the guideline in the UK is that either you have a family history, or you are under 40. He outlined that researchers have shown that your chance of a positive test result is 20% regardless of age, so it's important to test everyone. He outlined to respond to challenges in capacity this could be combatted by having dedicated genetic clinics, or using digital technologies to carry out genetic counselling.

In response to a question about possibly approaching the Wellcome Trust as a funding sources for research, Professor Al-Chalabi responded it would be an avenue to consider in future.

7. AOB

Andrew Lewer MBE MP thanked colleagues for attending and for Professor Al-Chalabi for his presentation. He outlined the secretariat would collate the minutes, share these on the website and circulate to all officers.