



**APPG ON MOTOR NEURONE DISEASE
ONLINE MEETING HELD ON FRIDAY 5 JUNE 2020**

NOTES

1. Welcome and introductions by the Chair, Andrew Lewer MBE MP

Andrew Lewer MP opened the meeting by welcoming attendees to the first ever virtual meeting of the Group and introduced the speakers.

2. The impact of Covid -19:

Amanda Solloway MP, Minister for Science, Research and Innovation

The Minister started by paying tribute to the late Professor Stephen Hawking and the role he played in increasing the profile of motor neurone disease (MND). She acknowledged the important ongoing work to understand more about the disease and find a cure. She explained that under the current circumstances, the Government has established a taskforce to ensure that Research and Development remains fit for purpose and is well supported.

The Minister acknowledged Covid-19 has caused disruption to the research sector and is working to ensure research remains high on the Government's agenda. There are many research projects that require completion and receive funding and, as part of the taskforce, the Department for Business, Energy and Industrial Strategy (BEIS) is working with the Department for Education to protect the stability of research going forward. This includes funding final year PhD students through support from UK Research and Innovation. The Department is looking to make sure paused research can restart as soon as possible.

The Minister offered to meet with the MND Association and the APPG.

Sally Light, CEO, MND Association

Sally outlined the challenges Covid-19 has created for the MND Association, including a predicted loss of income of a third (up to £5.5m) for 2020 and needing to refocus its activities to provide vital services for people affected by MND. To date The Association has not been eligible for any of the Government funding announced for charities.

Sally spoke about the campaign to get MND added to the list of conditions clinically extremely vulnerable to Covid-19 and, although not successful, the Association was very grateful for the support of the APPG and individual MPs.

The MND Association has a 40-year history of funding research, with a current portfolio of £14m. The research community believes it is on the cusp of real progress, but the pandemic has negatively impacted this. The Association has had to delay the start of several research projects, including a drug trial.

Sally called on the Government to support the sector at this important moment and welcomed the Minister's earlier comments.

Professor Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics, King's College London

If you would like a copy of Professor Al-Chalabi's slides, please email alison.railton@mndassociation.org

Professor Al-Chalabi highlighted current MND studies to find new treatments, including immune therapy, muscle strengthening, and gene therapy. The pandemic has had a significant impact on research, creating an unstable funding climate, particularly in the charity sector, and forcing clinical trials to be paused.

The UK is a world leader in many aspects of MND research, including in genetics studies like project MinE, the largest single disease sequencing project in the world. The UK has also been a leader in mapping, with the creation of the MND Register, which maps service provision versus need. Both projects face challenges due to the pandemic, from being unable to collect new samples for project MinE, to being unable to collect clinical information from hospitals for the MND Register.

The Government has a key role to play in enabling research by mitigating the effect of the pandemic on current and future research project funding, generally improving the funding landscape and reducing bureaucracy.

Jessica and Shaan, living with MND

You can view a video of Shaan and Jessica's speeches here

<https://www.mndassociation.org/mps-meet-virtually-to-discuss-the-impact-of-covid-19-on-people-with-mnd/>

Shaan was diagnosed with MND at the age of 32 and works full-time as an economist. He can no longer speak and uses eye-gaze technology to communicate. Shaan lives with his wife Jessica and 4-year-old son.

The family are currently shielding as Shaan is clinically extremely vulnerable. Jessica has been providing care for Shaan and trying to home-school their son. This has taken a significant physical and emotional toll.

Shaan and Jessica are anxious about what happens to those shielding as lockdown eases. They want the furlough scheme extended for families of shielded people and families who do not feel able to let their children return to school should be supported and are able to retain their school places.

They want paid carers to have fast access to PPE and testing, and to be provided with a car or bike so that they do not need to use public transport with the associated risks of picking up the virus.

3. Questions and discussion

Baroness Finlay asked about data collected on the impact of the pandemic on people with MND and their carers. Sally Light replied that data was being collected through the thousands of calls made to people with MND and this informs the Association's response to the pandemic.

MND Association Patron Eddie Redmayne asked what the Government should do to support people who are vulnerable, as wider society begins to enjoy wider freedoms. Professor Al-Chalabi replied there needed to be clear communication for individual circumstances and unpaid family carers should be able to remain at home. Sally Light advocated the need for improved testing and PPE and Shaan and Jessica suggested paid carers should have access to sick pay so they can remain at home if unwell.

Robert Goodwill MP asked about the pooling of global resources into MND research and the balance between investing in smaller and larger research institutions. Professor Al-Chalabi agreed pooled funding can be effective and pointed to projects funded by international charity coalitions. He cautioned not to overlook smaller research institutions, as sometimes they come up with new ideas. Jessica and Shaan raised their concerns about the development of a vaccine and whether those conditions named on the clinically extremely vulnerable list would be prioritised.

David Setters (living with MND) asked for greater Government investment in MND research to speed up access to effective therapies and ultimately a cure. Andrew Lewer said he would follow up on these points with the Minister. Professor Al-Chalabi reiterated that finding a cure should not be impossible, but that funding was critical.

Andrew Lewer thanked everyone for attending, thanked the speakers for their insightful contributions, especially Jessica and Shaan, and encouraged any further questions in relation to what was discussed to be directed to the APPG secretariat or his office.

Attendees:

Steve Baker MP	Vicky Foxcroft MP	Catherine McKinnell MP
Saqib Bhatti MP	Robert Goodwill MP	(researcher)
(researcher)	Chris Grayling MP	Esther McVey MP
Apsana Begum MP	(researcher)	Navendu Mishra MP
(researcher)	Margaret Greenwood MP	Jessica Morden MP
Paul Bristow MP	(researcher)	Mary Robinson MP
Felicity Buchan MP	Nia Griffith MP	(researcher)
Ian Byrne MP	James Grundy MP	David Rutley MP
(researcher)	(researcher)	Andrew Selous MP
Brendan Clarke-Smith	Rachel Hopkins MP	Amanda Solloway MP
MP	Christine Jardine MP	Julian Sturdy MP
Mims Davies MP	David Johnston MP	James Sunderland MP
(researcher)	(researcher)	Mark Tami MP
Martyn Day MP	Ruth Jones MP	Stephen Timms MP
Jack Dromey MP	Andrew Lewer MP	Liz Twist MP (researcher)
Philip Dunne MP	Scott Mann MP	Christian Wakeford MP
Marion Fellows MP	Jason McCartney MP	Jamie Wallis MP

Peers - Baroness Finlay of Llandaff and Lord Mackenzie of Culkein