



**AGM OF THE ALL-PARTY PARLIAMENTARY GROUP ON  
MOTOR NEURONE DISEASE**

**TUESDAY 9 JULY 2019**

**Present:**

Madeleine Moon MP (Chair)	Bridgend
Peter Aldous MP	Waveney
Paul Blomfield MP	Sheffield Central
David Drew MP	Stroud
Jack Dromey MP	Birmingham, Erdington
Rosie Duffield MP	Canterbury
Chris Evans MP	Islwyn
Gillian Keegan MP (researcher)	Chichester
Karen Lee MP	Lincoln
Andrew Lewer MP	Northampton South
Scott Mann MP	North Cornwall
Steve McCabe MP	Birmingham Selly Oak
Cat Smith MP	Lancaster and Fleetwood
Mark Tami MP	Alyn and Deeside

**In attendance**

Alex Massey – MND Association  
Cath and Ian Muir – person with MND/carer  
Marie Paclet – Marie Curie  
Dr Imran Rafi – GP Principal Senior Lecturer Primary Care Education, St George's University of London  
Alison Railton – MND Association and APPG Secretariat  
Daniel Vincent – MND Association  
Gurinder Jhans – Researcher for Madeleine Moon MP

**1. Welcome and introductions**

Madeleine Moon MP welcomed everyone to the meeting and those present introduced themselves.

**2. Minutes of the previous AGM**

The Minutes of the previous AGM and financial statement for 2017/18 were approved.

### **3. Election of Officers and appointment of secretariat**

The following Officers were elected to the APPG:

Chair	- Madeleine Moon MP
Vice-Chairs	- Christine Jardine MP - Andrew Lewer MP
Secretary	- Chris Evans MP

The Motor Neurone Disease (MND) Association was re-appointed as the Secretariat to the Group.

### **4. Reforming welfare for people who are terminally ill:**

#### **(i) Update from the Chair**

Madeleine Moon updated the group on her 10 Minute Rule Bill – the Access to Welfare (Terminal Illness Definition) Bill. There are no more sitting Fridays in the calendar so the Bill will not be heard again before the end of the session. Madeleine reported that she had met the Minister for Disabled People, Health and Work (Justin Tomlinson) that morning; there has been significant support from all political parties in Westminster for a change in the 6-month definition of a terminal illness; good media coverage via The Express and Huffington Post; celebrity endorsements; and the launch of the report by the APPG on Terminal Illness (copies were available at the meeting).

Another positive development had been the publication of new guidance by the Department for Work and Pensions (DWP) for clinicians signing DS1500 forms. The new guidance reminds clinicians that the DS1500 forms are for all terminal illnesses not just cancer and states that there wouldn't be any repercussions for clinicians if the person lives longer than 6 months.

#### **(ii) A personal perspective – Cath and Ian Muir**

Cath and Ian Muir had travelled from North Yorkshire to attend the APPG meeting. Ian spoke for Cath, as Cath's voice has been weakened by motor neurone disease (MND). Cath was diagnosed with MND in 2014 after 12 months of tests and uncertainty. Cath has a more slowly progressing form of the disease, but the couple have known people who have died within three months of diagnosis, people with young families and significant financial commitments. Cath applied for Personal Independence Payment (PIP) and the process was handled by the consultant neurologist at the hospital. The process worked very smoothly.

Madeleine Moon said Cath's experience showed the inequity in the current system, with access to the fast-track route largely determined by the willingness of a person's clinician to sign a DS1500. Madeleine Moon reminded attendees of two people with MND who had shared their experiences of claiming benefits at previous APPG meetings – Martin, who battled for 12 months to access Universal Credit, and James, a 29-year-old who was initially refused PIP and sadly died a year later.

### **(iii) A GP's perspective – Dr Imran Rafi**

Dr Rafi explained that he had been a GP for 20 years but had only cared for one patient with MND. He said that MND is a highly complex condition needing specialist input from neurology and palliative care teams. Dr Rafi explained that prognostication is very difficult in MND and other complex terminal conditions. UCL research into prognostic indicators had found that the accuracy of predicting life expectancy ranged from 20% to 70%. He argued that this illustrated the arbitrary nature of the 6-month rule for accessing benefits under the Special Rules for Terminal Illness. Dr Rafi believed clinicians would want to avoid the 'Scotland split' where devolved and reserved benefits would soon operate under different systems. There should be uniformity across the whole of the UK. Dr Rafi believed fast access and lifelong awards should be the norm for everyone with a terminal illness.

### **(iv) Discussion and next steps**

Madeleine Moon explained that the Minister had promised the definition of a terminal illness would be reviewed and the DWP wanted to involve a range of stakeholders in the review. DWP are speaking to the Scotland Team and have seen the draft guidance for Scotland. The DWP would be looking an international comparison as part of the review.

Steve McCabe expressed concern around the timescales and the review disappearing within the DWP. It will be important to keep the pressure on the DWP to ensure the review takes place.

David Drew stated that his PA's father has MND and asked what research into the disease is currently taking place. Madeleine Moon described the trail she is part of at UCL looking at MND, Parkinson's and dementia. Alex Massey (MND Association) explained that research was the number one priority for the MND Association but that we are starting from a much lower base than other conditions. The intention was to understand what causes the disease first and then develop effective treatments.

Gurinder Jhans (researcher) asked about the role of the GP in using their clinical judgement to determine if someone was terminally ill. Dr Rafi replied that a GP could make a clinical judgement with specialist input from an appropriate clinician.

## **5. AOB**

There was no other business, so the meeting was adjourned.