



**AGM OF THE ALL-PARTY PARLIAMENTARY GROUP ON
MOTOR NEURONE DISEASE
WEDNESDAY 12 FEBRUARY 2020**

Present:

Andrew Lewer MBE MP (Chair)
Peter Aldous MP
Kevin Brennan MP
Brendan Clarke-Smith MP
Rosie Duffield MP
Sir Iain Duncan Smith MP
Mark Fletcher MP
Mary Glendon MP
Nia Griffith MP
Andrew Gwynne MP
Trudy Harrison MP
Sharon Hodgson MP (researcher)
Christine Jardine MP (researcher)

Ruth Jones MP
Barbara Keeley MP
Clive Lewis MP
Jerome Mayhew MP
Steve McCabe MP
Jessica Morden MP (researcher)
Stephanie Peacock MP
David Rutley MP
Amanda Solloway MP
Mark Tami MP
Stephen Timms MP
Rosie Winterton MP

Lord Mackenzie of Culkein
Baroness Noakes
Lord Selkirk of Douglas

In attendance

Becky Gatenby - speaker
Chris James – MND Association
Alison Railton – MND Association and
APPG Secretariat

1. Welcome and introductions

Andrew Lewer MBE MP welcomed everyone to the AGM and outlined the agenda for the meeting. Andrew paid tribute to the work of Madeleine Moon, former chair of the APPG, and thanked her for her hard work, passion and dedication to people with motor neurone disease (MND) and their families.

2. Election of Officers and appointment of secretariat

The following Officers were elected to the APPG:

Chair - Andrew Lewer MP

Vice-Chairs - Brendan Clarke-Smith MP
- Chris Evans MP
- Christine Jardine MP
- Mark Tami MP

Secretary - Rosie Duffield MP

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

3. Reforming the welfare system for people who are terminally ill

(i) Introduction by Chris James, Director of External Affairs, MND Association

Chris James opened by talking about MND, and explained that it's a fatal, rapidly progressing disease that affects the brain and spinal cord. There are around 5,000 people in the UK with the disease and it kills a third of people within a year of diagnosis. The MND Association's vision is for a world free from MND and there has been tremendous progress in MND research over the last 10 years. This was significantly helped by funds raised worldwide from the Ice Bucket Challenge in 2014. Over the next two to three years, the MND Association hopes to see new treatments for MND coming through the system.

Chris reported that he had that morning been in Manchester on BBC Breakfast talking about MND following a media piece on three sportsmen who have been diagnosed with MND – Doddie Weir (rugby union), Rob Burrow (rugby league) and Stephen Darby (football).

Chris went on to talk about the problems people with MND face when they claim benefits and how the charity was campaigning to reform the welfare system so it better supports people who are terminally ill. At the moment a claimant can only receive fast-track access to benefits if they have a life expectancy of six months or less. This unfairly discriminates against people with unpredictable terminal illnesses like MND and means many people are forced to struggle with bureaucracy and wait weeks or months for their benefits.

Chris welcomed the review announced by the Department for Work and Pensions (DWP) last year and hoped it would result in positive changes for people with MND and other terminal conditions.

(ii) A personal perspective of claiming Universal Credit – Becky Gatenby

Becky Gatenby's father is living with MND and she described his experiences of claiming Universal Credit (UC). She explained that her father is 63 and had worked all his adult life. In January 2019 he had to give up his job as an HGV driver due to the loss of function in his hands. Six months later he received the devastating diagnosis that he had MND and was given a prognosis of two years maximum life expectancy. He had been claiming UC prior to his MND diagnosis and had needed to provide regular sick notes etc. He expected this to change when he informed the DWP about his diagnosis, but it didn't. Becky's father obtained a DS1500 form from his clinical team (the evidence needed to claim under the fast-track Special Rules for Terminal Illness). But the DWP refused to accept this and her father was told he needed to continue to provide sick notes and attend work capability assessments because he didn't fit the criteria of having 6 months or less to live. This meant that even though health professionals had deemed him terminally ill, the benefits system did not recognise it.

In August 2019 Becky's father's UC account was closed unexpectedly and he had to submit a new claim, painfully having to input all the information again. Becky's father experienced further problems when his next sick note was due – the GP surgery refused to issue any more sick notes due to her father's terminal diagnosis, saying it was a waste of their time. However, the DWP informed Becky that her father's UC account was at risk of closure if a sick note wasn't provided. They were caught in a standoff between two public sector agencies.

In desperation and not knowing who to turn to, they contacted the local hospital's MND team for advice who provided another DS1500 form. This time it was accepted by the DWP.

Becky believes the additional stress her father endured contributed to his rapid deterioration and she is angry that the precious time they had left could have been better spent. She said she has watched her father suffer due to his disease and suffer because of the benefits system. As Becky's father was too unwell to attend the meeting she finished with his words:

'Imagine being told that you are dying, that eventually you will be locked in your own body, like that isn't stressful enough without having to endure all the additional financial worries that UC adds to the terminally ill. It was degrading to feel that I had to beg for financial support from a system I had paid into most of my life. I felt abandoned and reduced to a number. The word terminal should be enough. It should not be about time as no one can guarantee how long the terminally ill will live, regardless of the prognosis. The criteria for the terminally ill needs to change before more people suffer at the hands of this system. Our story is just one of thousands. I am fortunate enough to have had my daughter and family to fight for me, not everyone has that support, I feel for those who have to fight this alone'

(iii) Questions

A number of MPs asked questions following the speeches. Peter Aldous MP asked about the time frame for the review. The Chair reported he had met with the Secretary of State for Work and Pensions and the Disabilities Minister that morning and the review was ongoing. No timeframe for its conclusion was given. Mary Glendon MP asked about GP training for benefits processes and suggested claimants should contact their MP if they experience problems. Lord Selkirk asked about MND research and reported that he had visited the Royal Infirmary in Edinburgh to see their research using zebra fish. Chris James responded that the MND Association's research portfolio totalled £16m but they wanted to see additional Government funding for MND research. Trudy Harrison MP asked about MND services in rural areas and Chris James reported that the MND Association funds 23 MND clinics across England, Wales and Northern Ireland (a separate organisation covers Scotland). A number of these clinics follow a 'network' model reaching out into more rural areas and reducing travel time for patients. Baroness Noakes asked about international collaboration and Chris James reported that the MND Association organises the annual International Symposium on MND – the largest gathering of MND scientists in the world.

(iv) Next steps

The Chair suggested that the next steps for the APPG were to encourage the DWP to conclude its review into how the benefits system supports people who are terminally ill and to make positive changes as soon as possible.

Alison Railton reported that the MND Association was due to launch some work on accessible housing and housing adaptations, as many people with MND struggle to access suitable housing quickly enough. The Chair suggested this could be the focus for the next meeting.

4. AOB

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