

All-Party Parliamentary Group on

Myalgic Encephalomyelitis (ME)

Annual General Meeting

Meeting Minutes

14 January 2020, 1 pm, PCH Room Q

Attendees

Alex Sobel MP Ben Lake MP Carol Monaghan MP Dame Diana Johnson MP Deidre Brock MP Fiona Bruce MP Gavin Newlands MP Hywel Williams MP James Davies MP James Sunderland MP Jonathan Reynolds MP Kerry McCarthey MP Liz Twist MP Margaret Greenwood MP Mary Glindon MP Michael Tomlinson MP Navendu Mishra MP Olivia Blake MP Robert Goodwill MP Sally-Ann Hart MP Stephen Metcalfe MP Stephen Timms MP Wayne David MP

Apologies

Andrew Selous MP Angus Brendan MacNeil MP Anne McLaughlin MP Baroness Scott of Needham Market Clive Lewis MP Debbie Abrahams MP Emma Lewell-Buck MP Gregory Campbell MP Jane Hunt MP Janet Daby MP Jason McCartney MP Jeffrey Donaldson MP Jerome Mayhew MP Julian Knight MP Julian Lewis MP Kevin Hollinrake MP Lord Gordon of Strathblane Mark Pritchard MP Paul Blomfield MP Paul Girvan MP Philip Davies MP Sharon Hodgson MP Tonia Antoniazzi MP

1. Welcome

The meeting began at 1 pm and was declared quorate by Carol Monaghan MP. Carol began the meeting by explaining her interest in ME and the aim of the new APPG to produce a report paper on key issues impacting ME sufferers.

The purpose of this inaugural meeting was to elect new officers and register the APPG.

2. Election of Officers

Six Officers were nominated to roles within the APPG: Chair (named contact): Carol Monaghan MP (SNP) Co-Chair: Stephen Metcalfe MP (Con) Co-Chair: Sharon Hodgson MP (Lab) Treasurer: Olivia Blake MP (Lab) Secretary: Hywel Williams MP (Plaid) Vice Chair: Ben Lake MP All Officers were elected.

3. AOB and Close

Carol Monaghan MP notified APPG members that the next meetings have been provisionally booked for the 11th February 2020 and 10th March 2020.

The proposed future meeting topics were then discussed briefly:

- 1. Access to healthcare as GET/CBT has proven ineffective
- 2. Access to financial support and welfare benefits e.g. Personal Independence Payment
- 3. Protection for children with ME
- 4. Biomedical research spending by the Medical Research Council (MRC) and National Institute

These were agreed upon with an addition of topics: (1) economic and societal impact of ME as a justification for additional spending (which was suggested by Stephen Metcalfe MP), and (2) medical diagnosis (which was suggested by Olivia Blake MP).

The Secretariat, Charles Shepherd from ME Association, then answered some questions on biomedical research updates.