

All-Party Parliamentary Group on

Myalgic Encephalomyelitis (ME)

# **Annual General Meeting**

**Virtual Meeting Minutes** 

29 March 2022, 10:00 - 10:30

### **Attendees**

## **Parliamentarians**

Carol Monaghan MP **Baroness Boycott** Baroness Finlay of Llandaff Baroness Masham of Ilton Luke Pollard MP Liz Twist MP Stephen Timms MP Patrick Grady MP Kerry McCarthy MP Cat Smith MP Caroline Ansell MP (representative) Alex Chalk MP (representative) Michael Tomlinson MP (representative) Stephen Morgan MP (representative) Hywel Williams MP (representative) Dr James Davies MP (representative) Jane Hunt MP (representative) Ian Levy MP (representative)

#### Secretariat

Dr Charles Shepherd, the ME Association Liam Ryan, Action for M.E. Caitlin Holmes, Action for M.E. Catherine Frazer, Office of Carol Monaghan MP

# **Apologies**

## **Parliamentarians**

Debbie Abrahams MP
Sharon Hodgson MP
Jason McCartney MP
Fleur Anderson MP
Baroness Scott of Needham Market
Stephen Metcalfe MP
Lord Selkirk of Douglas
Margaret Ferrier MP
Emma Lewell-Buck MP

#### 1. Welcome and introduction

Carol Monaghan MP welcomed all attendees and explained the meeting purpose which was to firstly fulfil the Annual General Meeting (AGM) requirements.

# 2. Key achievements of the year

Carol Monaghan MP provided an insight into the key achievements of the APPG over the past year:

- The APPG gathered evidence for the 1<sup>st</sup> APPG report on the issues facing people with ME in 5 key areas (research, healthcare, welfare benefits, children/young people, covid-19).
- The APPG met with representatives from the National Institute for Health and Care Excellence to welcome their new guideline on ME/CFS and discuss the implementation of the recommendations.
- The Chair met with officials from the Department for Health and Social Care to discuss the findings of the APPG and feed into their work on improving services for people with ME.
- Working with Forward ME to highlight the necessity of the new NICE guideline.

#### 3. Previous Minutes

The minutes from November meeting were agreed by members of the APPG.

## 4. Financial report

Carol Monaghan MP mentioned that the group does not need an income and expenditure statement as the group did not receive over £12,500 from outside Parliament in money or in kind.

### 5. Secretariat Changes

Carol Monaghan MP thanked Dr Charles Shepherd, Honorary Medical Advisor and Trustee of the ME Association, for his work to date in advising the APPG. Dr Shepherd will be continuing supporting the APPG in an advisory capacity and the ME Association, more broadly, will continue to provide support to the APPG as part of the Secretariat. Action for M.E., under the leadership of CEO Sonya Chowdhury, will be joining the Secretariat to increase capacity, providing administrative support, advice and financial support.

### 6. Election of Officers

The following Parliamentarians were nominated to officer roles within the APPG:

- Chair and Registered Contact: Carol Monaghan MP (Scottish National Party)
- Co-Chair: Stephen Metcalfe MP (Conservative)
- Co-Chair: Sharon Hodgson MP (Labour)
- Co-Chair: Baroness Scott of Needham Market (Liberal Democrat)
- Co-Chair: Baroness Finlay of Llandaff (Crossbench)
- Officer: Jason McCartney MP (Conservative)
- Officer: Dr James Davies MP (Conservative)
- Officer: Debbie Abrahams MP (Labour)
- Officer: Fleur Anderson MP (Labour)
- Officer: Hywel Williams (Plaid Cymru)
- Officer: Ben Lake (Plaid Cymru)

All Officers were elected.

# 7. Work Programme

The work programme for the upcoming year was discussed.

Carol Monaghan MP announced that a reception to launch the APPG report will take place on 25 May, between 3:00pm and 4:30pm. Invitations will be sent out in a couple of weeks to Parliamentarians and guests. This event will feature some special guests and input from the ME Community. It will be kindly funded by Action for M.E. and the ME Association.

Carol Monaghan MP plans to apply for a Backbench Business Debate to take place following the report launch. This will require APPG members to sponsor the application.

Other suggestions for future events were discussed by the attendees:

- A Q&A will a UK Government Minister on the report recommendations and what steps the UK Government is taking to support the implementation of the new NICE guideline.
- Public Q&A on the work of the APPG.
- Evidence sessions to delve deeper into the following topics: (1) clinical services and the new NICE guideline, (2) Social Care, (3) Long Covid, (3) ME research strategy.

#### 8. AOB and Close

Carol Monaghan MP to send a copy of the embargoed draft report to APPG officers and meeting attendees for final comments and edits.