

All-Party Parliamentary Group on

Myalgic Encephalomyelitis (ME)

# The impact of the COVID-19 pandemic on the ME community

# **Annual General Meeting**

Meeting minutes

19 April 2021, 11:00 - 12:00

#### **Attendees**

#### **Parliamentarians**

Carol Monaghan MP Jane Hunt MP **Baroness Meacher** Baroness Scott of Needham Market Steven Bonnar MP Cat Smith MP Sally-Ann Hart MP **Lord Tebbit** Stephen Metcalfe MP Jason McCartney MP Dr James Davies MP Chris Loder MP Marion Fellows MP (Representative) Michael Tomlinson MP (Representative) Siobhan Baillie MP Kerry McCarthy MP Ben Lake MP Hywel Williams MP (Representative) Olivia Blake MP Rachel Maskell MP

# Speakers

Dr Nina Muirhead Dr David Strain

#### Guests

Dr Charles Shepherd, ME APPG Secretariat Sonya Chowdhury, CEO, Action for ME

# **Apologies**

Marie Rimmer MP
Fleur Anderson MP
Sharon Hodgson MP
Debbie Abrahams MP
Jim Shannon MP
Baroness Hoey of Lylehill and Rathlin
Margaret Ferrier MP
Emma Lewell-Buck MP
Bishop of Carlisle
Luke Pollard MP
Stephen Timms MP
Lord Folkes of Cumnock

#### 1) Welcome

Carol Monaghan MP, Chair of the ME APPG, welcomed all attendees, guest speakers and the secretariat.

Carol Monaghan MP then explained the meeting purpose which was to firstly carry out the Annual General Meeting (AGM) and then discuss the impact of COVID-19 on the ME community.

#### 2) AGM Business

Carol Monaghan MP summarised the group's activities over the past year which included four evidence sessions looking at the key issues impacting people with ME in the UK.

It was noted by Carol Monaghan MP that the group does not need an income and expenditure statement and that the group does not receive any registerable benefits.

Officers were nominated to roles within the APPG:

- Chair and Registered Contact: Carol Monaghan MP (SNP)
- Co-Chair: Stephen Metcalfe MP (Con)
- Co-Chair: Sharon Hodgson MP (Lab)
- Co-Chair: Baroness Scott of Needham Market (Lib-dem)
- Officer: Jason McCartney MP (Con)
- Officer: Dr James Davies MP (Con)
- Officer: Debbie Abrahams MP (Lab)
- Officer: Fleur Anderson MP (Lab)

All Officers were elected.

#### 3) Presentations

- a) Dr Nina Muirhead, specialty doctor in dermatology surgery, Buckinghamshire Healthcare NHS Trust, and member of forward ME
  - This presentation provided an overview of the general challenges facing people with ME during the COVID-19 pandemic, the impact of the pandemic on training health professionals on ME, and the similarities between ME and Long Covid.

- b) Dr David Strain, Senior Clinical Lecturer, University of Exeter Medical School, and Honorary Consultant in medicine for the older adult
  - This presentation focused on the clinical and pathological overlaps between ME and other post-viral conditions, such as Long Covid, and the resulting challenges and opportunities in scientific research and medical care.

# 4) Updates

- a) Dr Charles Shepherd, ME Association Honorary Medical Adviser, ME APPG Secretariat
  - This update focused on (1) JCVI guidance and the place of ME patients in the COVID-19 vaccination programme and (2) the revised NICE ME guidelines.

## 5) Q&A Discussion

The following topics were covered:

- Debunking myths about ME
- Mandatory training for health professionals on ME
- Scientific research, for example, the Decode ME study
- Postural tachycardia syndrome (PoTS) and ME overlaps

## 6) AOB and Close

Carol Monaghan MP thanked the speakers for their insightful comments and suggestions.