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*All-Party Parliamentary Group on*



**Myalgic  
Encephalomyelitis (ME)**

# **All-Party Parliamentary Group for Myalgic Encephalomyelitis**

Minutes of the meeting on Severe ME held on 14 June 2023 in  
Room N, Portcullis House

## **Parliamentarians present:**

Carol Monaghan (Chair)

Jason McCartney MP

Dr. Julian Lewis MP

## **Apologies:**

Deidre Brock MP

Lord Wygley

Baroness Finlay of Llandaff

Lord Foulkes of Cumnock

## **In attendance:**

Sonya Chowdhury (APPG Secretariat and Chief Executive of Action for M.E)

Professor David Strain (University of Exeter Medical School; Action for M.E.  
Medical Advisor)

Anna Gregorowski (British Association of Clinicians in ME/CFS)

## **1. Welcome & Introductions**

Carol Monaghan MP welcomed parliamentarians and guests to the APPG's meeting in Westminster.

### **1.1 Election of Chair**

All parliamentarians present re-elected Carol Monaghan MP as Chair.

### **1.2 Election of Vice-Chairs and Officers**

All parliamentarians present re-elected Baroness Finlay of Llandaff, Stephen Metcalfe MP, Debbie Abrahams MP, and Sharon Hodgson MP as Vice-Chairs.

### **1.3 Election of Officers**

All parliamentarians present re-elected Fleur Anderson MP and Jason McCartney MP as Officers, as well as electing Marion Fellows MP as a new Officer.

## **2. Any Other Business**

Due to votes taking place in Parliament during the meeting, Carol Monaghan MP proposed that Any Other Business be discussed before the presentations.

2.1 Carol flagged her upcoming meeting with the Quadrum Institute, whose research involves ME, and extended the invite to the parliamentarians present.

2.2 Carol highlighted that the DecodeME survey continues to seek participants and urged parliamentarians to share details on their social media platforms.

2.3 Carol raised the question of recording and livestreaming meetings of the APPG. It was agreed that every effort would be made to record and make available the presentations made to the APPG.

2.4 Minutes from the AGM were formally approved.

2.5 The next APPG meeting is scheduled for the 8 November.

### **3. The Experience of Adults with Severe ME/CFS**

3.1 Helen Baxter from the 25% ME Group prepared a case study on the experience of an adult with severe ME/CFS. Due to connectivity issues, Helen could not join. Sonya Chowdhury read out Helen's case study in her absence.

### **4. Hospital Care – Challenges from a Medical Perspective**

4.1 Prof. David Strain made a presentation to the meeting on support in clinical settings, highlighting the trends in relation to cases of severe ME.

### **5. Specialist ME/CFS Services – Supporting People with Severe ME**

5.1 Anna Gregorowski outlined the structure, objectives, and vision of British Association of Clinicians in ME/CFS (BACME).

### **6. The Experiences of Children with Severe ME/CFS**

6.1 Sonya Chowdhury presented a case study of the experience of a child suffering from severe ME.

### **7. Questions & Answers**

7.1 Following the presentations, the parliamentarians present took part in a question & answer session.

The meeting ended at 5pm.

- The difficulty of treating severe ME given that hospitals often aren't attuned to patients' requirements
- The hope that current research into Long Covid will incorporate other post-viral syndromes and inform research on ME

## **6. Future Business**

- An APPG meeting on severe ME will be held in June
- There are plans for an APPG meeting on Immunology to be held after Summer Recess
- The ME APPG will look into potentially liaising with the Long Covid APPG

The meeting ended at 3pm.

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