



Annual General Meeting

Minutes of the Annual General Meeting held on 10 May 2023 at
2pm in Room W2, The Palace of Westminster

Parliamentarians present:

Carol Monaghan (Chair)
Stephen Metcalfe
Debbie Abrahams
Fleur Anderson
Julian Lewis
Ben Bradshaw
Baroness Bennett of Manor Castle
Baroness Meacher

Apologies:

Baroness Finlay of Llandaff
Sharon Hodgson
Jason McCartney
Marion Fellows
Ed Davey
Alex Chalk
Simon Jupp

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 Adviser;
Lejla Softic (Account Executive, Connect Public Affairs)
Tony Britton (PR and Fundraising Manager at the M.E. Association)

1. Welcome and Election of Officers

Carol Monaghan MP welcomed parliamentarians and guests to the APPG's Annual General 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. Discussion of the APPG's Income and Expenditure

Carol Monaghan MP informed the group that it received £2,000 in kind from outside Parliament in that reporting year via the joint Secretariat provided by Action for M.E. and the ME Association. This amount does not require that the group approve an income and expenditure statement as it falls below the £12,500 threshold.

3. Update from Carol Monaghan MP

Carol Monaghan MP updated the group on the recent actions she had taken in her capacity as Chair:

3.1 Carol has requested a meeting with the Secretary of State for Health and Social Care to discuss how DHSC plans to take the Delivery Plan forward.

3.2 Carol has requested a meeting with the President of the Royal College of Paediatrics and Child Health to discuss the need to improve outcomes for children with ME

3.3 Carol relayed the Government's response to her recently tabled Parliamentary Written Question on when they plan to publish the cross-Government Delivery Plan on ME.

3.4 There was a discussion of the need for a comprehensive pamphlet offering guidance and support to be handed out to patients and carers following an ME diagnosis.

3.5 The chairmanship of 'ForwardME' was discussed.

3.6 Carol let members know that she was looking to set up a meeting with the Quadram Institute in Norwich.

4. Presentation of Findings of Action for M.E.'s Embargoed Freedom of Information (FOI) Report by Sonya Chowdhury

Sonya shared the following with the group:

- An embargoed report on the findings from a recent Freedom of Information request to all NHS Trusts and Integrated Care Boards
- The report will be made public in June following a launch through the press/media which will also provide an opportunity for raising awareness and understanding of ME/CFS publicly
- Recommendations and opportunities for members to help drive these.

5. Discussion of severe ME with Professor David Strain

Professor David Strain spoke to the group about:

- The significant increase in severe ME cases over recent years

- 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.