



All Party Parliamentary Group on M.E.

Chair: Sir Peter Bottomley MP
Co-Chair: Countess of Mar
Vice-Chair: Mark Tami MP
Secretary: Jacob Rees-Mogg MP

Notes from the All-Party Parliamentary Group on M.E. meeting, Thursday 17 March 2016, 2pm to 3pm, Room Q, Portcullis House

Present

Parliamentarians

Sir Peter Bottomley MP
Peter Aldous MP
Representative from Mark Tami MP
Representative from Siobhan McDonagh MP

Secretariat

Declan Mullaney, Action for M.E./Whitehouse Consultancy
Dr Charles Shepherd, ME Association

Organisations

Mary-Jane Willows, Association of Young People with M.E.
Janice Kent, reMEMber
Bill Kent, reMEMber
Jane Colby, Tymes Trust
Anita Williams, Tymes Trust
Catherine Ross, The 25% ME Group
Hannah Clifton, ME Trust
Dr Paul Worthley, ME Trust

Apologies

Parliamentarians

Countess of Mar	Mark Garnier MP
Jacob Rees-Mogg MP	Sir Oliver Heald MP
Graham Brady MP	Ben Howlett MP
Stephen Pound MP	Seema Kennedy MP
Hannah Bardell MP	Ian Liddell-Grainger MP
Heidi Alexander MP	Caroline Lucas MP
Nicola Blackwood MP	Steve McCabe MP
Graham Brady MP	Kerry McCarthy MP
Tom Brake MP	Ian Murray MP
Richard Burden MP	Jeremy Quin MP
Alex Chalk MP	Sir Nicholas Soames MP
Geraint Davies MP	Keir Starmer MP
Michael Gapes MP	Dr Philippa Whitford MP
	Hywel Williams MP

Secretariat and organisations

Sonya Chowdhury, Action for M.E.
Kathleen McCall, Invest in ME

Sue Waddle, ME Research UK
Christine Harrison, BRAME

1. Welcome by the Chair

DM apologised on behalf of Sonya Chowdhury who was unable to attend the meeting due to illness, and asked for him to stand in as Chair on her behalf. DM gave a brief overview of his role working alongside Action for M.E.

2. Social care inquiry

DM gave an update on the APPG-led inquiry, launched following the publication of Action for M.E.'s *Close to Collapse* report. The final inquiry report, to be published through the APPG, was still planned for the summer following a policy roundtable on Tuesday 19 April. DM noted that the invites had been sent out for the roundtable, however if there were stakeholders that were particularly relevant that members wished to suggest they should contact the Secretariat.

DM informed the meeting that the roundtable was aimed at policy makers, local authorities and social care providers and those involved in the social care process, rather than for members or the general public, as spaces were limited.

Participants raised the possibility of extending the remit of the inquiry to include medical assessment as this was a precursor to those with M.E. receiving a social care assessment. However, it was agreed that in order for the report and the inquiry to put forward clear and targeted suggestions, the inquiry should remain focussed on social care.

DM asked participants about barriers facing people with M.E. from accessing social care, as these could then be considered for discussion as part of the wider inquiry. It was noted that one of the key barriers was recognition of the illness and that more needed to be done to improve training and education for health and social care workers. It was agreed that this should be included within the inquiry.

A participant raised concerns about the repeated references in the report that imply that an increase in activity is safe for people with M.E. DM suggested this was an issue that should be followed up via email with the Secretariat.

3. Awareness-raising drop-in session for MPs

DM informed the group of the drop-in session for MPs on Wednesday 11 May between 12.30pm and 2pm in Portcullis House. This included plans to draft a letter that members and affiliates could send to their MPs to ask them to attend and learn more information, acting as a representative on their behalf.

It was also agreed that producing an information pack for MPs would be helpful, so that when they were approached by constituents with M.E. they had the correct information and knew where to signpost people for help or advice.

4. Forward planning

DM asked those present to consider future subjects beyond the social care inquiry which the APPG could focus on, so that momentum can be maintained following the conclusion of the inquiry. Participants raised the possibility of conducting a review of existing services, as this hadn't been undertaken in at least 12 years. It was suggested that further research was needed to find out if similar reviews had been conducted of other services or clinics.

Due to time constraints it wasn't possible to cover this agenda in much detail and it may be explored at the next meeting.

5. Research update

CS gave an update on recent research: the UK CFS/M.E. Research Collaborative has opened registration for its conference in Newcastle in September and noted that details are available on the ME Association and Action for M.E. websites. The ICAFS is holding its bi-annual conference in October in Fort Lauderdale, US and both members of the joint secretariat were planning on attending.

The issue of the NICE guidance was raised and whether the outcome of the Information Commissioner's Officer ruling re the release of data from the PACE trial would affect future changes to the guidance. A watching brief will be taken.

6. Date of next meeting

The next meeting of the APPG will be its Annual General Meeting and will take place on Wednesday 11 May at 2pm following the drop-in session for MPs.

7. Any other business

No other business was raised.