



All Party Parliamentary Group on M.E.

Chair: Sir Peter Bottomley MP
Co-Chair: Countess of Mar
Kerry McCarthy MP
Julian Sturdy MP
Carol Monaghan MP
Vice-Chair: Mark Tami MP
Secretary: Daniel Zeichner MP

Minutes of the All-Party Parliamentary Group on M.E. Annual General Meeting, Wednesday 7 September 2016, 1 to 2.30pm, Room S, Portcullis House

Present:

Parliamentarians:

Sir Peter Bottomley MP, Chair
Countess of Mar, Co-Chair
Kerry McCarthy MP
Julian Sturdy MP
Carol Monaghan MP

Secretariat:

Sonya Chowdhury, Action for M.E.
Katie McMahon, Action for M.E. (minute-taker)
Dr Charles Shepherd, ME Association

Organisations:

Sue Waddle, ME Research UK
Janice Kent, reMEMber
Bill Kent, reMEMber
Cath Ross, The 25% M.E. Group
Barbara Robinson, Suffolk Youth and Parent Support Group (guest)
Catherine Hale, Action for M.E.
Hannah Clifton, ME Trust

Apologies:

Graham Brady MP
Daniel Zeichner MP
Jane Colby, Tymes Trust
Christine Harrison, BRAME
Tanya Harrison BRAME

1. AGM business

Julian Sturdy MP proposed and Kerry McCarthy MP seconded the elections of Sir Peter Bottomley MP as Chair, Countess of Mar as Co-Chair, Mark Tami MP as Vice-Chair and Daniel Zeichner MP as Secretary. They were unanimously elected.

Countess of Mar proposed and Julian Sturdy MP seconded the election of Kerry McCarthy MP and Carol Monaghan MP as Co-Chairs. Countess of Mar proposed and Kerry McCarthy MP seconded the election of Julian Sturdy MP as Co-Chair. They were unanimously elected.

Sir Peter Bottomley left the meeting as he had another meeting to attend. Countess of Mar took over chairing the meeting.

Actions: No further action required.

2. *Canary in a coal mine*

The Producer and UK Impact Producer of the film shared information about Jennifer Brea's forthcoming documentary film about M.E., due for release in 2017. Due to a news embargo, no minutes are recorded for this item.

3. Social care inquiry

Countess of Mar shared her concerns that MPs need to consider all the evidence about the current state of affairs before agreeing recommendations as per previous inquiries. She felt that decisions could not be made at the APPG meeting. Sonya Chowdhury agreed and identified that Daniel Zeichner MP, as Inquiry Chair, would lead these discussions with APPG members to ensure consideration of a draft report (which would include an Executive Summary), submitted evidence, evidence from the Roundtable discussion and the recommendations; consultation with charity colleagues who participate in APPG meetings would contribute to these discussions.

Sonya suggested that she and Countess of Mar have a discussion with Daniel on the process of the inquiry and agreed to convene this meeting in October.

Charles Shephard said that it is important that the Inquiry and its recommendations have maximum impact.

Cath Ross emphasised that it is necessary to communicate to MPs the reality of the situation that people with M.E. find themselves in. For example, people being refused care. While much-needed research is going to take time, measures to address such experiences as these can have a much more immediate impact on the lives of people with M.E.

Sonya highlighted that the terms of reference for the inquiry had already been approved, which Sir Peter Bottomley had been involved in. In terms of inputting into the report, there are examples readily available of people being refused care, and who do not have access to services. What is required as an output from the inquiry to address the neglect that people with M.E. experience is one or two ambitious policy goals alongside some quick wins.

Catherine Hale stated that the *Close to Collapse* report focussed on the experience of people with M.E. in relation to their access to social care and gave a good representation of the current state of affairs. More case studies could be included in this final report, if required, in order to inform and ground the recommendations.

Cath Ross suggested that legal advice could be sought on the duty of the local authority, and this aspect could be incorporated into the recommendations if appropriate.

Actions: Daniel Zeichner MP, Countess of Mar and Sonya Chowdhury will convene to discuss the process of the inquiry.

4. 2016-2017 planning

Sonya Chowdhury highlighted that there is a need to set a programme of work for the APPG with some tangible outputs that will improve the lives of people with M.E. Sonya added that there will be some recommendations that the APPG will wish to prioritise following the output from the inquiry. Additionally, she suggested consideration given the issues that she and colleagues are aware of.

The group agreed with this and Countess of Mar suggested joining with other illness groups who have difficulty with diagnosis citing discussions she has had with other APPGs.

Sonya will explore the potential to set up a separate meeting based around issues of diagnosis with representatives from other illness groups as a springboard for joint work.

Members were invited to consider other aspects of work that the APPG could focus on in advance of the next meeting.

Actions: Sonya Chowdhury will explore setting up a meeting with representatives from other illness groups.

5. AOB

Countess of Mar shared that following her correspondence with Jill Mizen, she would be tabling written questions regarding the Parliamentary and Health Service Ombudsman.

Countess of Mar highlighted the continuing medical education programme, used by Atos healthcare, where M.E. is classified as two types of condition: a neurological condition and a neurotic stress disorder. It was agreed that the Countess of Mar will contact James Bolton (DWP) to clarify whether this (version seven) is the final version and if so, to question the classifications given that they do not reflect the classification of M.E. as neurological by the World Health Organization.

Cath Ross referenced discussion at a recent Forward M.E. meeting in the House of Lords that GPs aren't routinely recording cases of M.E. which therefore makes it challenging when assessing needs such as that required through the Joint Strategies Needs Assessments. In contrast, one local authority had started to record incidence of M.E. and could be used as an example of good practice.

Sonya Chowdhury raised how the group could work together in future, by uniting around a common strategy to achieve a common goal to improve the lives of people with M.E. This should be forward-looking and be something that all could agree to focus time and energy on as APPG colleagues. She gave the example of the resource for MPs which had been a success, and supported by charity partners.

Sue Waddle suggested a task and finish focus on diagnostic issues for people with M.E. given that diagnosis creates a pathway for further support (such as access to social care).

Actions: Countess of Mar will contact James Bolton to receive clarification on the continuing medical education programme, and to raise concern with the classification of M.E. if necessary.