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All Party Parliamentary Group on M.E.



Chair: Des Turner MP
Vice-Chairs: Andrew Stunell MP
Tony Wright MP
Secretary: Countess of Mar
Treasurer: David Amess MP

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Minutes of the meeting of the All Party Parliamentary Group on M.E.
held at 1.30-3pm, Wednesday 8 July 2009
Committee Room 13, House of Commons

Present:

Parliamentarians

Dr Des Turner MP
Andrew Stunell MP
Countess of Mar
Peter Luff MP
Edward Davey MP

Secretariat

Sir Peter Spencer (Action for ME)
Heather Walker (Action for ME)
Kimberley Hogarth (Action for ME)
Charles Shepherd (MEA)

Organisations and individuals

Paul Davis (RiME)
Jane Colby (Tymes Trust)
Christine Harrison (BRAME)
Doris Jones (25% Group)
Joy Birdsey (K&SAME)
Jill Cooper (Warwickshire Network for ME)
Bill Kent reMEMber)
Janice Kent (remember)
Augustine Ryan
Michelle Goldberg

Apologies:

1. Welcome

The Chairman welcomed those present and apologised to those who may have been inconvenienced by a change of room. Two further

apologies were made: that unfortunately there would be no speaker today, and that the chair would have to leave the meeting at 2 p.m. but that the Countess of Mar had kindly agreed to complete the meeting.

2. Annual General Meeting

Current officers were re-elected with the exception of Dr Ian Gibson, who had resigned as an MP. The Countess of Mar was elected to replace him. The elected Officers for 2009-2010 are therefore:

Chair: Dr Des Turner MP
Vice-Chairs: Andrew Stunell and Anthony Wright
Treasurer: David Amess
Secretary: Countess of Mar

The Chair pointed out that he is not standing at the next general election, so a new Chair will have to be found at that point.

3. Minutes of the last meeting

The Chair reminded the Group that the minutes are not intended as a verbatim record; they are business minutes. However he accepted that Paul Davis had said at the last meeting: "There is a road map that goes back to the CMO report, York review 1, and a certain school of psychiatry." The reference to the CMO report had been omitted from page six of the transcript.

4. Matters arising

Jane Colby asked that it be noted that the BBC Politics Show, filmed in part during the last meeting, was transmitted in ME awareness week, and that everybody was very grateful to the APPG for allowing it to happen.

5. APPG Inquiry into NHS Services

The Chair reported that evidence sessions were due to start at 2pm the next day in Committee Room 19. The first session would hear from patients and patient organisations. He hoped that the next week's session would include a Minister, the Chief Medical Officer and service providers. Many patients had submitted evidence. Questionnaires had been sent to all Primary Care Trusts. The aim was to produce a report which would act as a campaigning tool to improve services for people with ME.

During the discussion which followed, Dr Turner had to leave and the Countess of Mar took the chair. Some concerns were raised eg. that:

- i. Existing services were not focused on neurological ME and over-emphasised the psychosocial model

- ii. Some people would not respond to the survey for that reason
- iii. Some panel members had made favourable comments about existing services in the past
- iv. Evidence sessions clashed with key local meetings elsewhere, affecting attendance
- v. People submitting evidence had not received confirmation of receipt due to the inquiry's lack of administrative support
- vi. Publicity for the inquiry had been limited and would not reach the majority who were not in touch with certain charities, support groups or services
- vii. Some patients do not collate evidence
- viii. How issues not covered by surveys, such as the replacement of consultants by new services in some areas, could be addressed.

Some issues could be raised via questions through the panel eg. support for severe cases.

It was noted that the decision had been taken by parliamentarians at the last meeting, to drive forward the inquiry quickly, because of the imminence of a general election.

The hope was for a report by the inquiry which would have sufficient credibility, evidence and parliamentary authority for consideration by the Health Select Committee.

6. Statement from WMMEG (West Midlands ME Groups) Consortium on ME/CFS - Education and Training in the NHS

- i. Heather Walker apologised formally for tabling the wrong statement on their behalf at the last meeting.
- ii. Jill Cooper asked that sufficient time to be allocated to discuss the key issues of appropriate NHS training at a future APPG meeting.
- iii. Sir Peter Spencer responded to the WMMEG statement saying that he did not believe that NHS staff were being 'trained' to treat this illness as a psychological illness and that Action for M.E.'s involvement in the last NHS collaborative conference had resulted in delegates hearing Professor Stephen Holgate emphasise the importance of getting new research talent into the field, plus discussion on the need for properly derived patient reported outcome measures.
- iv. Noting to the statement's reference to Pathways to Work, the Countess of Mar reported that the Welfare Reform Bill was going through the House of Lords. She had been fighting hard to have ME and other fluctuating conditions recognised in their own right by the Grand Committee and not "lumped in" with mental illness.

The meeting acknowledged its appreciation of all the work that the Countess had done.

7. Future Work of the APPG

Ideas included:

- i. Inviting Baroness Young, Care Quality Commission, to address the Group
- ii. Maintaining focus on the DWP and Welfare to Work
- iii. Follow-up on the presentation made by Jane Colby and Mary-Jane Willows about child protection problems, by asking the Inspector of Social Services to come to the APPG to listen to parents, consider how social services might be alerted to the possibility of M.E. in children and examine how parents could be informed of their rights eg. through a simple leaflet signposting information and organisations that could help them.

8. All Party Parliamentary Group Legacy Paper

As a General Election was due and the Chair had noted his intention to stand down, it was suggested that it might be useful to draw up a short summary of the APPG's recent activities, outstanding concerns and objectives for consideration by the new Chair and any other new officials.

People with M.E. could be invited to put forward three or four bullet point suggestions for the key issues and objectives and to submit them to Heather Walker, Action for ME and Charles Shepherd. On behalf of the Secretariat, Action for M.E. would produce a draft consensus document from the results.

Action: Heather Walker to supply a copy of the Legacy Paper produced by the Cross Party Group on ME in the Scottish Parliament before their last General Election.

Legacy Paper (*copy and paste address into browser*):

<http://www.afme.org.uk/res/img/resources/Scottish%20CPG%20on%20ME%20Legacy%20Paper%20-%20March%202007.pdf>

9. Website

A website had been set up for the APPG at www.appgme.org.uk. Although the impetus for the site had come from the inquiry, the site would continue after the inquiry and would be the central focal point of information about meetings and activity.

10. Any Other Business

Michelle Goldberg raised the case of Kay Gilderdale 54 and the assisted suicide of her daughter, Lynn, after 17 years of M.E.

Michelle described the lack of support she herself had faced and highlighted problems experienced by another woman proven innocent after receiving an ASBO.

Christine Harrison reported on her campaign about pets in holiday accommodation. Currently, customers with allergies can not be guaranteed a holiday property in which a registered guide and/or support dog has not stayed. The Countess of Mar had kindly taken this up in the House of Lords, asking for a new clause to be added to the Disability Discrimination Act to say that people who rent out holiday accommodation are permitted/allowed to have a policy of no pets and no smoking to allow them to offer accommodation to guests who may have health conditions and/or allergies that might be exacerbated by the presence of pets and smoke.

11. Date of Next Meeting

The chair advised the group that the next meeting would be in the Autumn