

CFS/ME Expert Group

Minutes of the 3rd meeting held on 1st March 2010

MRC Head Office, 20 Park Crescent, London W1B 1AL

In attendance:

Professor Stephen Holgate (University of Southampton – Chairman)
Professor Philip Cowen (University of Oxford)
Dr Esther Crawley (University of Bristol)
Professor Hugh Perry (University of Southampton)
Dr Derek Pheby (National CFS/ME Observatory)
Professor Anthony Pinching (Peninsula Medical School)
Dr Charles Shepherd (ME Association)
Sir Peter Spencer (Action for ME)
Professor Peter White (Bart's and the London School of Medicine and Dentistry)

MRC

Dr Rob Buckle
Dr Joanna Latimer (Secretariat)

1. Chairman's welcome, introduction & apologies

- 1.1 The Chairman welcomed members to the third meeting of the Group and thanked everyone for giving up their valuable time to attend.
- 1.2 Apologies had been received from Professor Jill Belch (University of Dundee), Professor Malcolm Jackson (University of Liverpool), Dr Jonathan Kerr (St George's University of London) and Professor Ian Kimber (University of Manchester).

2. Minutes of the 2nd Meeting held on 30th March 2009

- 2.1 Members agreed the minutes from the previous meeting as an accurate record of the meeting.

3. Update on work of CFS/ME charities

- 3.1 Sir Peter updated the Group on three current projects:
 - The M.E. Observatory project funded through the Big Lottery Fund was nearing completion.
 - The Action for ME funded post mortem tissue archive feasibility study was completed towards the end of 2009. A second phase study examining the feasibility of setting up an *in vivo* tissue bank was being jointly funded by Action for ME and the ME Association.
 - The National Outcomes Database project was nearing completion.

Further funding opportunities were being explored by the charities and lead investigators for follow on projects.

4. Update on further research studies investigating the link between XMRV and CFS/ME

4.1 It was noted that following on from the original US study linking XMRV and CFS/ME three further studies have been completed, two from UK groups and one from a group in the Netherlands. None of these studies had shown any association between the retrovirus and CFS/ME. Furthermore, it was noted that the study from the Netherlands had used the same primers and techniques for detecting the retrovirus as those used by the US group.

4.2 Members agreed that an independent double-blind study of a previously untested independent group of well-defined patients would help to reconcile the different outcomes of the studies and help clarify whether there is an association of XMRV with CFS/ME.

5. Discussion of the CFS/ME research workshop

5.1 Members agreed that the workshop had provided a very good collaborative environment and highlighted the main issues that were currently compounding research in the area of CFS/ME. These included:

- The definition of fatigue and the associated difficulties in measuring fatigue.
- Difficulties of acquiring well-characterised cohorts without a concrete definition or measures. It would be important that sufficient raw data and characterisation of phenotypes was made available to all researchers from all studies to help resolve this issue.
- Broad based phenotypes versus single phenotypes – a more broad-based approach would allow for sub-categorisation of phenotypes.
- Lack of prioritisation - the priorities identified were extensive however not all were tractable at the current time.

5.2 It was agreed that a systems approach was needed to tackle this disease and it remained important to bring new people into the field with the relevant expertise. However, without a clear list of tractable priorities it would be difficult to achieve this. Members suggested that a small prioritisation group be convened comprising of relevant experts from both the CFS/ME field and outside who had participated in the workshop. This group would be tasked with prioritising the areas identified at the workshop that were tractable in the shorter and medium term. This group would report back to the Expert Group at the next meeting.

6. Date of next meeting

Members agreed that the next meeting should be held in the autumn 2010 once the Prioritisation Group had met. The secretariat would circulate potential dates in due course.

7. Close

The Chairman thanked members once again for their valuable contributions and closed the meeting.