

CFS/ME Expert Group Meeting

To be held on Monday 15th December 2008 at 13:15

Location: MRC Head Office – Room A

Lunch will be provided from 12:30

Agenda

Time	Agenda	Lead	Paper
1. 13:15	Welcome & apologies	Professor Holgate	
2. 13:25	Declarations of Interest		
3. 13:35	Terms of Reference	Professor Holgate	
4.1 13:45	CFS/ME Research – Where are we now and what are the current research questions?	Professor Holgate	
4.2 13:55	Genetics and CFS/ME	Professor Holgate	Paper 1
4.3 14:05	Immunology and CFS/ME	Professor Pinching	
4.4 14:15	Paediatric CFS/ME & Clinical Centres	Dr Esther Crawley	
4.5 14:25	CFS/ME and Treatment	Professor Peter White	
4.6 14:35	National CFS/ME Observatory	Dr Derek Pheby	Paper 5
4.7 14:45	Charity perspective	Sir Peter Spencer & Dr Charles Shepherd	
5. 14:55	Tea and Coffee		
6. 15:05	What are the research opportunities and the way forward?	Professor Holgate	
7. 16:05	Summary	Professor Holgate	
8. 16:15	Date of next meeting		
9. 16:20	Close		

Enc: Paper 1: Genetics and CFS/ME
 Paper 5: National CFS/ME Observatory

Annex 1: Background information: Annex 1a: CFS/ME literature review
 Annex 1b: Current MRC funded CFS/ME research
 Annex 1c: Summary report of 2003 MRC CFS/ME Research Advisory Group
 Annex 1d: Report of 2006 M.E. Research Summit

CFS/ME Expert Group

Minutes of the 1st meeting held on 15th December 2008

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

In attendance:

Professor Stephen Holgate (University of Southampton – Chairman)
Dr Esther Crawley (University of Bristol)
Professor Malcolm Jackson (University of Liverpool)
Professor Ian Kimber (University of Manchester)
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 first meeting of the Group and thanked everyone for giving up their valuable time to attend. Introductions were made round the table.
- 1.2 Apologies had been received from Professor Jill Belch (University of Dundee), Professor Philip Cowen (University of Oxford), Dr Jonathan Kerr (St George's University of London) and Professor Hugh Perry (University of Southampton).

2. Declarations of interest

- 2.1 Members were informed on the MRC Policy on Declaration of Interests and asked to return their completed forms to the Secretariat.

3. Terms of Reference

- 3.1 The Chairman referred members to the draft Terms of Reference and asked that these be revisited at the end of the meeting once discussions had been heard. Members were asked to consider the following questions during the meeting and when the Terms of Reference were discussed:
 - 1) Where could the UK be strong in CFS/ME research?
 - 2) Which areas of the CFS/ME field could be made more competitive and how could this be achieved?

4. CFS/ME Research – Where are we now and what are the current research questions?

- 4.1 Professor Holgate gave the Group an overview of the strategy developed by the previous 2003 MRC CFS/ME Research Advisory Group and outcomes of the 2006 Action for ME/MRC Research Summit. Whilst research had progressed from that time, there still remained problems that made research in this area difficult. These included the lack of well-defined phenotypes and the heterogeneity of the condition.
- 4.2 Members noted the CFS/ME literature review provided at Annex 1 of the meeting papers. Research into CFS/ME covered a diversity of disciplines which further underlined the complexity of this condition, however, there was an opportunity for interacting with researchers from outside the CFS/ME field but in related areas such as fatigue and immunology that in turn could inform on CFS/ME. Furthermore, there were opportunities for capitalising on improvements in new technologies such as 'transcriptomics' and 'proteomics', which might lead to improved diagnosis and stratification of patient groups.
- 4.3 Professor Holgate emphasised the importance of working together with existing resources/activities at the national level, such as the existing clinical research networks and the National CFS/ME Observatory. It would also be important to consider how to attract leading scientific experts into the field and how to encourage young scientists to focus on CFS/ME.
- 4.4 Members noted Paper 1 – Genetics and CFS/ME - that had been provided by Dr Jonathan Kerr. Members agreed that it would be important for researchers in this area to collaborate as large-scale studies were needed to identify sub-phenotypes of CFS/ME. Furthermore, if such studies were conducted at a national level, there was scope for ensuring that sample collection and control classification followed the same protocols to aid in comparative studies and the establishment of well-defined cohorts. More substantive research could then follow on from the initial pilot studies in the longer-term.
- 4.5 Professor Pinching led the discussion on 'Immunology and CFS/ME' and outlined the current state of research in this area. Key questions and opportunities remained:
 - Pathogenetic mechanisms – cytokine action; dysregulation of immune function.
 - Epidemiology – infective triggers; non-infective and perpetuating triggers; disease associations; need well-defined clinical and longitudinal cohorts.
 - Clinical/Translational – Collation of clinical observational data; characterisation of interaction of co-morbidities; characterisation of functional and cognitive deficits; validation of existing and new outcome measures; pilot interventional studies (standardised, focused); systematic studies of patient-clinician interactions.
 - Social/Cultural - identity & disease; invisibility; paradigms; alienation; importance of recognition that there is a problem to solve.

To take advantage of opportunities it would be important that there was recognition that there is a problem to solve and work together with patients

and researchers in partnership. It would also be important to work together with international collaborators.

- 4.6 Dr Crawley led the discussion on 'Paediatric CFS/ME and Clinical Networks', outlining the current research in this area and the current questions and opportunities. As with adult CFS/ME, the difficulty of defining paediatric CFS/ME prevalence was highlighted as a key issue and it would be important to continue paediatric longitudinal cohorts. Continued health services research and evidence based service provision was also needed.
- 4.7 Professor White led the discussion on current research and opportunities in 'CFS/ME and Treatment'. Members noted that there were currently two ongoing trials in the UK in this area both of which were funded by the MRC, the PACE trial and the FINE trial. Opportunities in this area included using the existing networks (for example using intervention studies to analyse pathophysiology), establishing databases and cohorts, and collaborating with international researchers to set up 'virtual' centres that would enable the sharing of resources.
- 4.8 Members noted Paper 5 provided by Dr Pheby which outlined the work of the National CFS/ME Observatory. Dr Pheby highlighted that prevalence studies were needed and that it would be important to have uniform case definition internationally to allow for comparability of data.
- 4.9 Sir Peter and Dr Shepherd highlighted the charity perspective on CFS/ME research and the expectations of the community for this new Group. Sir Peter outlined the role of Action for ME and Dr Shepherd the role of ME Association and both charities provided information as to the research funded by both of these charities. Key issues raised were how to encourage young people into the field and the need for more funding in this area. Members noted that 8 of the charities in this area had begun to meet up regularly in a new initiative – 'Forward M.E.'. A list of research projects funded by CFS/ME research charities was tabled.

5. What are the research opportunities and the way forward?

- 5.1 The importance of collaboration was highlighted as a key issue in helping research move forward in the field of CFS/ME. It was noted that CFS/ME research was currently quite fragmented and by setting up a collaborative approach would help in the following areas:
 - prevention of duplication of effort
 - lead to joined up resources and funding
 - would bring in existing national resources such as the clinical networks
 - would help in looking at the bigger agenda.
- 5.2 Members discussed the possible ways for increasing research in CFS/ME. Members agreed that a workshop that built on the previous research summit was one way forward. However, in order to engage the interest of researchers from related fields, the workshop should also address the related areas outside of the direct CFS/ME area, such as fatigue, pain, malaise and cognitive impairment, which are relevant to aspects of the condition. This would have several benefits to CFS/ME research. Firstly, leading scientific experts who may have previously considered research in

CFS/ME outside of their field may become engaged and bring different perspectives and research ideas that would be of benefit to CFS/ME. Secondly, this could also stimulate an increase in young people beginning to work in the field of CFS/ME. Furthermore, CFS/ME researchers might gain in terms of access to new resources and technologies. Thirdly, a workshop would allow dialogue between researchers and patient groups to reassure them that CFS/ME remained a research priority and that high-quality research was feasible.

6. Discussion of Terms of Reference

The Chairman asked the Members on their thoughts on the draft Terms of Reference. It was agreed that these should be expanded to take into consideration the discussions held during the meeting. Revised Terms of Reference would be circulated to the Group by the secretariat and agreed at the next meeting.

7. Date of next meeting

The Chairman thanked all those who attended and suggested that this was the start of a new look at the field in which both the MRC and the Patient Charities were involved. Members agreed for the next meeting to be held in spring 2009. The secretariat would circulate potential dates in due course.

8. Close

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