

## MRC CFS/ME Expert Group

### Minutes of the 2<sup>nd</sup> meeting held on 30<sup>th</sup> March 2009

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

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#### **In attendance:**

Professor Stephen Holgate (University of Southampton – Chairman)  
Professor Philip Cowen (University of Oxford)  
Dr Esther Crawley (University of Bristol)  
Professor Malcolm Jackson (University of Liverpool)  
Dr Jonathan Kerr (St George's University of London)  
Professor Ian Kimber (University of Manchester)  
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)

#### **MRC**

Dr Rob Buckle  
Dr Joanna Latimer (Secretariat)

#### **1. Chairman's welcome, introduction & apologies**

- 1.1 The Chairman welcomed members to the second 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) and Professor Peter White (Bart's and the London School of Medicine and Dentistry).

#### **2. Minutes of the 1<sup>st</sup> Meeting held on 15<sup>th</sup> December 2008**

- 2.1 Members approved the minutes from the previous meeting as an accurate record, though agreed that an addendum be included that outlined the work of the CFS/ME Clinical and Research Network Collaborative as well as the work of the National Observatory.

#### **3. Terms of Reference**

- 3.1 The Chairman referred members to the revised draft Terms of Reference. Following discussions, the Group agreed that the Terms of Reference needed to incorporate encouragement of new researchers into the field. It was agreed that revised Terms of Reference would be circulated to members for final approval.

#### **4. Update on work of CFS/ME charities**

- 4.1 Sir Peter Spencer and Dr Charles Shepherd updated the Group on progress with the feasibility study for a Post-Mortem Tissue Bank for CFS/ME.
- 4.2 It was agreed that determining a good clinical phenotype would be key for the success of the proposed bank. This could be aided through setting up longitudinal and natural history studies in addition to a tissue archive. This would be an important area for discussion for the workshop.

#### **5. Discussion on a CFS/ME research workshop**

- 5.1 The Group discussed the format for the research workshop. It was agreed that this would be a small working event attended by CFS/ME researchers, researchers from outside the field and representatives from charities involved in research.
- 5.2 An overview of current research should be included, and this would be best achieved by providing the participants with a literature review. A two day meeting, from lunchtime to lunchtime, would allow sufficient time for an overview of research in key thematic areas to be presented through short talks, followed by a second day of discussions by small groups tasked with identifying research priorities.
- 5.3 An integrative approach would be important in helping to understand the causes of CFS/ME, and this should be reflected in the thematic areas highlighted for the short talks. The following areas were identified for these presentations:
  - phenotyping and epidemiology
  - autonomic dysfunction including cardiovascular dysfunction
  - fatigue
  - sleep
  - pain
  - neuropsychology
  - imaging
  - new technologies and technological platforms
  - neuroendocrinology
  - immune dysregulation
  - infection
- 5.4 It would be important to try and bring in leading experts in the above areas from outside of the CFS/ME field, and ideally some of the talks should be presented by such experts. Opening the workshop up to researchers from other fields should provide an opportunity for new expertise to be brought in and could, in time, lead to increased engagement from the outside community.
- 5.5 Areas for consideration by the discussion groups on the second day of the workshop should include the following questions:
  - how can capacity in the field be increased?
  - where are the UK strengths, in the context of international competition, and how could relevant links be forged?
  - are there new technologies and/or technological platforms that could help move the field forward?

**6. Date of next meeting**

Members agreed that the next meeting should be held following the workshop. 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.