

MRC CFS/ME Research Prioritisation Meeting

4th June 2010

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

Present

Participants

Professor Hugh Perry (University of Southampton) (Chair)
Professor Anthony Pinching (Peninsula College of Medicine & Dentistry)
Professor Philip Cowen (University of Oxford)
Professor Maria Fitzgerald (University College London)
Professor Paul Moss (University of Birmingham)
Professor Julia Newton (University of Newcastle)
Professor Paul Little (University of Southampton)

Observers

Dr Charles Shepherd (ME Assoc)
Mr George Armstrong (Action for ME)

MRC Office representatives

Dr Rob Buckle
Dr Jo Latimer
Dr Leanne Rivers

Apologies

Professor Steven Holgate (University of Southampton)
Sir Peter Spencer (Action for ME)
Professor Peter White (Barts and the London)
Professor Alan Rickinson (University of Birmingham)

1. Welcome and introductions

- 1.1 The Chair welcomed everyone to the meeting and thanked them for giving up their valuable time to attend. Introductions were made around the table.
- 1.2 The Chair outlined the aims of the group, which were to identify appropriate short, medium and long term goals for researchers in fields relevant to CFS/ME.

2. Outcomes of discussion

- 2.1 The following outcomes were agreed

1) CFS/ME is a real, serious and debilitating medical condition, and that research into all aspects of CFS/ME is needed. This message, previously stated by the MRC in "CFS/ME RESEARCH STRATEGY" (May 2003), needs to be re-emphasised and promoted more widely to engage clinicians, basic scientists and patient groups.

2) Cross-disciplinary research that explores the central biological questions of relevance to CFS/ME should be actively encouraged. While acknowledging the challenges in CFS/ME, such as difficulties with diagnosis and collecting early onset patient data, the scientific community

is well placed to investigate the pathways and symptoms that are common to CFS/ME and other conditions. Experts in the field of pain, fatigue, autonomic dysfunction, cognitive symptoms, sleep disorders and infections and altered immune function would be welcome to submit collaborative proposals to explore these issues in CFS/ME and associated disorders/areas of research that could bring important information to bear on CFS/ME.

3. Prioritisation of research topics

3.1 The research topics and issues that were raised at the MRC CFS/ME Research Workshop in November 2009 were discussed. Short, medium and long term goals were agreed as follows:

Short term

- Research to address mechanisms underlying chronic changes through the study of cross-disease symptomology and pathways in the clinic and/or lab:
 - Autonomic dysfunction
 - Cognitive symptoms
 - Fatigue
 - Immune dysregulation (eg. through viral infection)
 - Pain
 - Sleep disorders
- Capacity building, including bringing in expertise from other relevant fields.

Medium term

- Co-morbidity and chronicity
- Susceptibility and resilience
- Mitochondrial function and energy metabolism
- Utilising existing well characterised cohorts including the assimilation of those coming through clinical services
- Developing interventions, such as cytokine inhibition, by adapting the use of antiviral agents and compounds effective at treating similar symptoms in different diseases.

Longer term

- Developing imaging technologies
- Genetic risk (once issues relating to phenotypic heterogeneity have been clarified)
- Neurobiological changes, for example patterns of cerebral activity.

Other important issues

- Developing animal models to mimic specific symptoms and allow pathway analysis
- Psychological research to explore the relationship between precipitating and perpetuating factors
- Longitudinal population based studies to gain insight into the development and life-course of CFS/ME
- Phenotypic definition (currently there are between 3 and 6 different phenotypes in clinical use, with an additional 3 paediatric phenotypes)
- Improving detection and diagnosis, e.g. development of assessment tools
- Development and improvement of outcome measures, esp. patient reported outcomes

- Standardisation of measurements and assessments
- Improvement in data collection tools
- Access to tissue, for example a biobank for early diagnosis, post mortem and control tissue.

4. Close of meeting

The Chair closed the meeting and thanked all participants for attending.