

ME Research UK currently funded ME/CFS projects

At present, we fund the work of a growing number of scientists, some listed below (our website lists others).

Autonomic dysfunction and its consequences — a clinical cohort study (clinical fellowship)

Prof. Julia Newton, University of Newcastle

Vitamin D Status and its association with cardiovascular function

Dr Faisal Khan, University of Dundee

SNPs within CFS-associated human genes

Dr J Kerr, St George's University of London

Non-invasive structural and functional neuroimaging

Prof. BK Puri, MRC Clinical Sciences Centre, Imperial College London

An investigation into biochemical and blood flow aspects of ME/CFS in children

Dr Gwen Kennedy, University of Dundee

Focal and global endothelial function and their association with arterial stiffness

Dr Faisal Khan, University of Dundee

Post-exertional malaise in ME/CFS: the role of intracellular immunity and sensory processing

Dr Jo Nijs, University College Antwerp

Medical Research Council:

In May 2003, the Medical Research Council (MRC) announced its “research strategy for CFS/ME”, widely welcomed as the first formal research strategy for the illness. It listed a number of strategic themes of particular importance (case definition, epidemiology, pathophysiology, interventions, health service research, research capacity and the value of lay participation). Subsequent initiatives by the MRC included the issue of a notice highlighting CFS/ME as a current strategic priority (2003), a CFS/ME workshop (2003), and a “Joint Action for ME” workshop (2006).

So, what research has since been funded? Well, at least five separate studies (see the sidebar on the opposite page) costing at least £3,180,900 have been supported. From the bald titles, it is impossible to determine what each involves, but it seems that three fall far short of being definitive (one is for “indirect support”, one is for a “CFS-like illness”, and one is simply a feasibility study, albeit an expensive one), while the remaining two are randomised clinical trials (RCTs) of psychosocial strategies.

From details published in the National Research Register (before it ceased publication in October 2007), we know that the largest (PACE) trial is a four-arm RCT comparing cognitive-behavioural therapy (CBT), graded exercise therapy (GET), adaptive pacing and “usual medical care” alone. As its blurb explained, “CBT will be based on the illness model of fear avoidance... GET... on the illness model of deconditioning and exercise avoidance”.

The FINE trial, by contrast, offers severely affected patients supportive listening, GP “treatment as usual”, or a

nurse-led self-help approach which includes elements of CBT and GET delivered in the patient’s home (four 90-minute sessions, with six 30-minute phone conversations over 18 weeks), with a qualitative interview to explore “patient views on illness causation, beliefs about chronic fatigue... and previous experience of treatment and doctor-patient relationships”.

In total, approximately 91% of the total grant-spend on ME/CFS in five years has gone on trials of non-specific management and coping strategies. It is important to point out, however, that neither of these trials is actually worthless; in an ideal world in which £100 million had been invested over five years in ME/CFS research, a 3% spend on assessing the usefulness of various coping strategies, such as CBT, relaxation or meditation, might have been acceptable. The point at issue is that most of the MRC’s inadequate grant-spend has gone on this aspect at the expense of truly biomedical research, the reverse of the situation in other illnesses such as multiple sclerosis or rheumatoid arthritis. Even the dogs in the street would think this record dismal.

Thanks to the Freedom of Information Act, and the stalwart patients who have repeatedly requested information, we have a (fuzzy) picture of the research projects which the MRC has NOT funded to June



Cartoon by Trish Campbell

a case to answer?

2008. They seem to total at least 33 (see the table below), some biomedical and targeted at pathophysiology. It is unlikely that these 33 applications were so badly written that they could be rejected (since some were from established researchers with a track record in this and other fields, as our personal communications have established). So, was their scientific basis less sound than, say, the “pragmatic rehabilitation” of the FINE trial, supported by RCT data on ambulant patients but only a case report on the non-ambulatory patients of particular interest?

There are three main schools of thought about what has gone on. First, that within the MRC the biopsychosocial model of ME/CFS is the current paradigm, leading referees and committee members to be chosen, probably unwittingly, to deliver a

particular outcome (since psychosocial aspects colour the perception of the illness across the board, this would be no surprise). Second, that the MRC is simply a large stolid bureaucracy for which ME/CFS biomedical research has very low priority indeed given the other demand on its resources (£1.3 billion in 2008 for all types of research on all illnesses). Third, that something even more fishy is going on.

In the summer of 2008, an answer to a parliamentary written question revealed that the MRC is to constitute a CFS/ME multi-disciplinary panel. If this is a genuine attempt to kick-start biomedical investigation rather than a public relations exercise, the mystery panel's first act could be to discover whether or not the MRC has a case to answer over the non-funding of biomedical research since 2003. ●

Table. Unfunded applications to the MRC between 2002 and 2008

<i>Time-frame</i>	<i>“CFS/ME” Subject area</i>
<i>2002 to 2005 (11 total)</i>	<i>Neurophysiology of fatigue; Population-based/epidemiological studies (4 applications); Neurotransmitters and stress; Neuroimaging; Clinical and laboratory characterisation (physiology/diagnosis); Dietary intervention — RCT; Facilitated self-help — RCT; Psychosocial and genetic factors in young people</i>
<i>2005 to 2006 (12 total)</i>	<i>Pathophysiology, including studies regarding genetics/biomarkers, immunology and neuroimaging (7 applications); Population-based/epidemiological studies (3); Primary care study; Experimental medicine study</i>
<i>2006 to April 2007 (7 total)</i>	<i>Cognitive outcomes in children — pathophysiology; Epidemiological studies — epidemiology; Biomarkers; Pathophysiology (2 applications); Molecular pathogenesis — pathophysiology; Molecular and genetic characterisation — pathophysiology; Neuroimaging — pathophysiology</i>
<i>May 2007 to June 2008 (3 total)</i>	<i>Biomarkers — pathophysiology; Management and treatment — intervention; Management and treatment — observational study</i>

MRC currently funded “CFS/ME” projects

(Sources: MRC website; Hansard, written answers)

Two large clinical trials of new approaches to treating CFS/ME:
 a) PACE (Pacing, Activity and Cognitive Behaviour Therapy: a Randomised Evaluation, £2,076,363) [Prof. PD White, Psychological Medicine, Queen Mary and Westfield College]
 b) FINE (Fatigue Intervention by Nurses Evaluation, £824,129) [Dr AJ Wearden, Psychological Science, Uni. of Manchester]

A preliminary epidemiological project to test the feasibility of identifying the risk factors for persistent symptoms of fatigue and abdominal and widespread pain (£118,263) [Prof. F Creed, Psychological Medicine, University of Manchester]

An epidemiological study to assess ethnic variations of the prevalence of a CFS-like illness, associations with potential risk factors, and coping behaviours (£162,145) [Prof. K Bhui, Cultural Psychiatry and Epidemiology, Queen Mary and Westfield College]

Indirect support through a trial exploring the management of patients with persistent unexplained symptoms [Specifics unknown]

One project was mentioned in Hansard (12th June 2008) but is not on the MRC website: General and specific risk markers and preventive factors for chronic fatigue and irritable bowel syndromes (£367,000) [Dr C Clark, Centre for Psychiatry, Barts and The London School of Medicine]