

FOR UK PARLIAMENTARY INQUIRY INTO ME/CFS

**Chronological list of documents relevant to the Inquiry authored by
Professor Malcolm Hooper, Eileen Marshall and Margaret Williams**

7th November 2005

Most of the articles mentioned in this document are on the internet; all are available from Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, Department of Life Sciences, University of Sunderland, SR2 7EE, UK.

Note that Myalgic Encephalomyelitis (ME) is listed in the World Health Organisation International Classification of Diseases also as chronic fatigue syndrome (CFS) and as PostViral Fatigue Syndrome (PVFS). In the US, the disorder is sometimes known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), whilst the current preference by some international researchers is for the term Neuro-endocrine-immune Dysfunction Syndrome (NDS), which they maintain more accurately reflects the underlying pathology. It is important to be aware that this disorder is not, as claimed by some psychiatrists, synonymous with chronic unexplained fatigue (to which these psychiatrists unhelpfully refer as “CFS”).

Introduction

Our views are already on record in a preliminary submission of 18th August 2005 prepared for this Inquiry (ME: Why No Accountability? A synopsis for the UK Parliamentary Inquiry), but this short introduction will hopefully emphasise the seriousness of the problem.

We submit that, for almost two decades, the beliefs and actions of a small but influential group of UK clinicians and researchers from the discipline of psychiatry have been responsible for not only a hindering of progress in the understanding of the biomedical disorder myalgic encephalomyelitis (ME) and for the consequent lack of appropriate NHS provision of services for sufferers, but also for the psychiatric bias that, since 1987, has pervaded the UK medical literature concerning this disorder.

We note that since psychiatry became fashionable, almost all conditions for which no specific cause was instantly apparent have, in the first instance, been labelled “psychiatric”, but that following scientific research, virtually all those conditions proved to be organic in nature. The pontifications of the psychiatrists at the time are still extant and now make amusing reading, but presumably the unfortunate sufferers themselves were unamused. Since such scenarios have occurred so frequently, one would imagine that by now, caution in diagnosis would be automatic until scientific research had been exhaustively pursued, but in the case of ME, the opposite has occurred: appropriate research into ME has been made almost impossible in the UK, with researchers other than psychiatrists being starved of funds; clinics that specialised in authentic ME have been closed and NHS consultant contracts not renewed, and the results of biomedical research from abroad have been ridiculed and rejected.

Due to the relentless efforts of psychiatrists whose vested interests have now been exposed, the view has gained credence that it is acceptable to regard those with ME who are not willing to receive a psychiatric diagnosis as being “undeserving of treatment” (quoted from a lecture given in October 1999 at Strathclyde University by Professor Michael Sharpe [see below], who then disingenuously asserted that such a view is deplorable and that he was merely paraphrasing Bernard Shaw’s ‘Pygmalion’). So that Parliamentary Inquiry Members may judge for themselves, Sharpe’s actual words were: “Purchasers and Health Care providers with hard pressed budgets are understandably reluctant to spend money on patients who are not going to die and for whom there is controversy about the “reality” of their condition. They are in this sense undeserving of treatment. Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain – to paraphrase Bernard Shaw -- the undeserving sick of our society and our health service”.

We submit that these psychiatrists have been responsible for the promotion of a potentially damaging psychiatric management regime of cognitive behavioural therapy (CBT) that includes a programme of

graded exercise, CBT being described in the “independent” report to the UK Chief Medical Officer of January 2002 as “a tool for constructively modifying attitude and behaviour” (Report Summary, Annexe 6, page 8).

Evidence exists that shows CBT is at best ineffective and at worst harmful in authentic ME, resulting in severe relapse that may be lifelong.

Attention is drawn to the current issue of PULSE, 29th October 2005, pages 14-15, which highlights the death of a 46 year old woman from Cardiff who died at a supervised gym following a GP referral. The medical defence organisations have repeatedly warned doctors that exercise programmes must be prescribed with the same degree of care as drug prescriptions and the item in PULSE noted that a study in the Journal of Public Health found that a small minority of GPs were responsible for the vast majority of exercise referrals; it noted that legal concerns are once again in the news, and that many GPs were reluctant to make referrals because of the lack of evidence and concerns over medico-legal responsibility.

The group of psychiatrists and supporters involved has become colloquially known as the “Wessely School” (see Hansard [Lords]: 19th December 1998:1013), so named after psychiatrist Professor Simon Wessely from King’s College Hospital and The Institute of Psychiatry, London, whose published personal views on the non-existence of ME are prolific. Other prominent members of the Wessely School include psychiatrists Professor Peter White from St Bartholomew’s Hospital, London and Professor Michael Sharpe, formerly of Oxford but now at Edinburgh: their involvement, as that of their like-minded colleagues, is documented in the literature listed below, most notably their long-term close association with the medical insurance industry.

The influence of this group of psychiatrists is extensive throughout UK Government Departments, the NHS and even the Judiciary: one severely affected litigant in a High Court action was informed that “Judges regard ME as self-indulgence”.

In 1999, the Countess of Mar, a stalwart campaigner for the UK ME community, obtained the Opinion of a Leading Queen’s Counsel in the House of Lords; the eminent QC’s Opinion stated:

“On the document you have sent me there is an overwhelming case for the setting up of an immediate independent investigation as to whether the nature, cause and treatment of ME as considered by the Wessely School is acceptable or consistent with good and safe medical practice. There is substantial doubt as to whether such could be the case. A formal request should be made to set up such an enquiry at which interested parties could be represented by Counsel”.

Attempts to do so have been unsuccessful until the present good auspices of Dr Ian Gibson MP (former Chairman of the Commons Science and Technology Select Committee and former Dean of Biology at the University of East Anglia) have made it possible, to whom the UK ME community owes considerable gratitude.

We ourselves submitted 92 pages of accurate references published in reputable medical and scientific international journals that provided convincing evidence of the organic and serious multi-system nature of the disorder to both the Chief Medical Officer’s Working Group and to the Medical Research Council during their respective deliberations on the direction of future research into what they both refer to as “CFS/ME”. The reason this term is used was explained by Wessely himself: “It may seem that adopting the lay label (of ME) reinforces the perceived disability. A compromise strategy is ‘constructive labelling’: it would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term CFS/ME reflects such a compromise” (BMJ: 2003:326:595-597).

For ease of reference, the papers were broadly divided into sections that included historical papers on ME (1938-1980); general papers on ME (i.e. papers that addressed multi-system anomalies, for example the evidence of impaired oxygen delivery to muscle and evidence of delayed recovery from fatiguing exercise, as well as balance and visual problems); laboratory findings in ME; quality of life in ME; chronicity and severity in ME; precipitating factors in ME; epidemiology of ME; neuroendocrine abnormalities in ME; neurological abnormalities in ME; evidence of demyelination in ME; ocular

problems in ME; virology in ME; overlap of ME with Post-Polio Syndrome; chemical injury to the blood brain barrier; immunology in ME (including evidence of hair loss and mouth ulcers in ME); allergies and hypersensitivities in ME; anaesthesia problems in ME; vascular problems in ME; cardiac problems in ME; respiratory problems in ME, gut dysfunction in ME; liver and pancreatic involvement in ME; brain imaging anomalies seen in ME; cognitive dysfunction in ME; gynaecological problems in ME; special problems in children with ME, and the similarities and differences between ME and fibromyalgia.

On each occasion, our submissions were comprehensively ignored by the Government bodies concerned.

Some of our documented concerns and supportive evidence were also passed by the Countess of Mar to appropriate government officers for presentation to the Chief Medical Officer and to the Director of the Benefits Agency Medical Services, with a request by Lady Mar for a detailed response. The answer came in a written response from an MP: it had been decided at Ministerial level that our evidence should be ignored and that no action be taken.

The documents listed below provide a paper-trail record of our concerns that the increasing incidence and prevalence (and even the very existence) of a serious neuro-immuno-vascular disorder are being denied by UK Government bodies due to the malign influence of Wessely School psychiatrists.

1994

The Views of Dr Simon Wessely on M.E.: Scientific Misconduct in the Selection and Presentation of Available Evidence?

Eileen Marshall and Margaret Williams

The CFIDS Chronicle: Spring 1994:14-18

The article provided direct quotations from Wessely's published work on ME/CFS, including several for which he has become notorious, for example, that ME exists only because of patients' 'maladaptive coping strategies'; that ME is simply one end of a continuum of 'tiredness'; that it is nothing more than an attitude problem experienced by suggestible people who see ME as an easy escape route from life's problems; that 'a little more psychology and a little less T cells (i.e. immunology) would be welcome'; that any observed abnormality of muscle function may result from physical inactivity; that on examination of those with ME, "the usual findings of simulated weakness were present"; that those with ME exhibit "learned helplessness"; that "the description given by a leading gastro-enterologist at the Mayo clinic remains accurate: 'the average doctor will see that they are neurotic and he will often be disgusted with them' ".

Note: Simon Wessely personally threatened the UK distributors of The CFIDS Chronicle with an injunction unless they promised to deface every copy and remove our article before distributing the Spring issue in the UK; Wessely's threats were acted upon, but copies that came direct from the US were not defaced. People in the UK were outraged that copies for which they had paid in advance had been defaced even without an injunction.

Letters to the Editor: Simon Wessely Follow-up

Eileen Marshall Margaret Williams

The CFIDS Chronicle: Summer 1994: 77-79

Our reply to Wessely's response pointed out that, contrary to what he stated ("I run the only free service solely dedicated to the needs of patients with CFS/ME between the River Thames and the Coast"), in the UK there is a National Health Service and that this means that *all* patients can receive free treatment, and that there were at the time numerous other NHS Consultants who ran clinics south of the River Thames specifically for ME patients. We also pointed out that, contrary to his claims, he was not "principal expert witness in two medico-legal cases concerning CFS" but was in fact one of three medical expert witnesses in both cases. We also noted that, since Wessely asserts that he does not recognise ME as a distinct entity but includes all people with chronic fatigue under the single label of CFS, his claim that "research has shown that our rehabilitation programmes are proving successful"

needs to be questioned, because we have no idea about how many of his patients actually have ME. We also noted that it is sadly true that Wessely has changed the facts about ME; that he has indeed misrepresented the valid findings of other researchers and that he does indeed ignore important findings that do not support his own views and, bearing this in mind, we felt justified in querying whether or not this amounted to scientific misconduct.

1995

UK Task Force Report: CFS/M.E. is Real

Eileen Marshall and Margaret Williams

The CFIDS Chronicle: Spring 1995: 22-23

This document summarised the UK National Task Force Report from Westcare, September 1994, pointing out that the Report was unequivocal in its conclusion that progress in understanding ME is hampered by the use of heterogeneous study groups and definitions of "CFS", by the lack of standardised laboratory tests, and by the invalid comparison of contradictory research findings stemming from these factors.

1996

Conference Report: Transcript of Lecture given on 23rd November 1995 at the Coventry and Warwickshire Post-Graduate Centre by Professor Peter Behan.

Margaret Williams (using the pseudonym Julia Hamilton)

InterAction No.21: Summer 1996

This document notes that Professor Behan stated that although the diagnosis remains essentially one of exclusion, there *are* now laboratory techniques that will confirm the diagnosis; that the acute fatigue is exactly the same as that seen in conditions such as multiple sclerosis; that by using refined techniques for measuring gait disturbance and by measuring muscle power, a phenomenal drop in maximum oxygen consumption is apparent; that there is very early excessive intracellular lactic acidosis with exercise and that this tends to persist; that patients with ME have reduced levels of acylcarnitine (carnitine being an amino acid used in mitochondrial oxidation); that there is abnormal liver function; that there is abnormal immune function in ME; that there is a central cellular deficit giving rise to other abnormalities and that ME is an *organic* illness. The document noted that Professor Behan made sure that the audience was left in no doubt about his view of those psychiatrists, often powerful, who have brought to patients with ME what Behan termed '*enormous trouble*'.

Denigration by Design? A Review, with References, of the Role of Dr Simon Wessely in the Perception of Myalgic Encephalomyelitis 1987-1996. Volume I pp 217.

Eileen Marshall Margaret Williams August 1996

This compendium considered the various terminologies for the disorder; definition difficulties; Wessely's tactics of dismissal and his relentless denial of the evidence of organic disorder; illustrations of research findings and opinions with which Wessely disagrees; extensive quotations from Wessely's published work (so there can be no denial of his views on ME/CFS); Wessely's obvious lack of balance; questions that Wessely might usefully be required to answer, such as where is his evidence to support his assertions that those with ME obtain "secondary gain" by "adopting the sick role", and a review of the losses sustained by those with ME that Wessely never once addresses or even mentions.

Note that the document included a mini-review of some of the published works on ME/CFS by Dr Anthony David (a frequent co-author with Wessely), famous for his beliefs about ME that include: "A diagnosis of depressive illness would be appropriate. Unfortunately, this is not good enough for the patient"; "self-help organisations have established 'ME' in the minds of the public"; "doctor behaviour, such as sick certification, emerged as a significant contributor to the risk of chronic fatigue" and "clinicians should avoid reinforcing unproven illness beliefs".

Observations on the Joint Report of the UK Royal Colleges of Physicians, Psychiatrists and General Practitioners on Chronic Fatigue Syndrome, CR54, October 1996.

Eileen Marshall Margaret Williams 17th November 1996

This document exposed the psychiatric bias that pervaded the Report and provided illustrations of how research evidence had been manipulated by the Report's authors to look as if it supported their own views when the cited references did not support them at all. In the Joint Royal College's Report, Wessely et al specifically state the following: 'ME' does not exist; patients wish to keep the term 'ME' because only with that label are they eligible to call upon the welfare state for help; the dysfunctional beliefs of CFS/ME patients have an important place as an obstacle to recovery; CFS/ME is a somatisation (psychiatric) disorder; no investigations should be performed to confirm the diagnosis; there is no convincing evidence of any change in muscle structure or function other than those secondary to inactivity; immunological abnormalities "should not deflect the clinician from the endorsed (psychiatric) approach and should not focus attention towards a search for an 'organic' cause"; there is no compelling evidence linking immune dysfunction with disability; there is no reason for the creation of specialist units; specific guidelines for the management of ME should not be issued to general practitioners; the need for future research is regarded as unnecessary; complementary therapy is discouraged but antidepressants should be prescribed for those with "CFS" even in the absence of depression (advice that would seem to reflect HealthWatch policy --see below).

1997

Comparison of the American Report for Physicians on CFS (September 1996) with the UK Joint Royal Colleges' Report on CFS (October 1996)

Eileen Marshall Margaret Williams 20th February 1997

This document highlighted the difference in approaches to the management of ME in the UK and the US, for example the US Report stated it is important to note that up to 40% of carefully evaluated patients do not have psychiatric illness; that patients should be treated with compassion; that there is a greatly increased incidence of allergies; that there should be a reasonable laboratory workup; that patients should be referred to professionals who can help with applying for disability benefits and that patients benefit from participation in support groups; that the disorder is a multisystem illness with prominent central nervous system (CNS) involvement and that in the case of children, the physician should work with the school to limit class time and that home tutoring may be an alternative. In stark contrast, the UK Joint Royal Colleges' Report stated that children may need to be forcibly removed from their homes and parents and that there should be an immediate return to school; that nothing but the most basic screening tests should be carried out; that involvement with a support group is a predictor of poor outcome; that 75% of CFS patients have psychiatric illness; that patients with allergies may fulfil criteria for somatisation disorder; it concluded that chronicity is likely to be associated with unaddressed psychosocial issues.

1999

Denigration by Design? A Review, with References, of Dr (now Professor) Simon Wessely in the Perception of Myalgic Encephalomyelitis. UP-DATE: 1996-1999 Volume II pp 271

Margaret Williams November 1999

Like the first volume in 1996, this compilation provided further illustrations of international research evidence on ME/CFS that Wessely School psychiatrists dismiss, trivialise or ignore, together with accurate quotations from their own published work. It included a section illustrating psychiatrists' track record of mis-attribution and considered areas where Wessely has clearly been shown to be wrong, for example, the Camelford catastrophe, in which 20 tonnes of aluminium sulphate were accidentally pumped into the drinking water supply in July 1988 at Camelford, in which residents and visitors suffered distressing symptoms such as nausea and vomiting, diarrhoea, skin rashes, musculoskeletal pains, with malaise and impairment of memory; in some cases hair, skin and nails turned blue; seven people died; 25,000 suffered serious health effects and 40,000 animals were affected, but which Wessely authoritatively dismissed as mass hysteria and anxiety (whereas other competent non-psychiatrist researchers found organic brain damage to have occurred).

The compilation considered 13 conclusions in relation to Wessely's public pronouncements on ME, including his view that ME is a "myth" caused by patients' belief that they are suffering from a disorder called ME.

The document also included a 20 page summary of some of the findings presented at the Second World Congress on Chronic Fatigue Syndrome and Related Disorders held in Brussels, 9-12th September 1999, in which evidence was presented on the biochemical and microbiological aspects of the disorder, as well as on the disrupted immunology and on the epidemiology; specifically, it was noted that a total cardiovascular work-up reveals that frequently there are CNS vascular occlusions in ME and that vasculitic patterns are identical to those seen in HIV patients: SPECT and PET scans show that huge areas of the brain are injured.

2000

Consideration of Some Issues Relating to the Published Views of Psychiatrists of the 'Wessely School' in relation to their belief about the nature, cause and treatment of myalgic encephalomyelitis (ME)

Margaret Williams, with Appendices by Val Broke-Smith and Ann Crocker March 2000

Because the two volumes of "Denigration by Design?" were so detailed, it was suggested that a condensed version be produced. This document looked at the then current situation; at the evidence that psychiatrists of the Wessely School were wrong about ME, and at the tactics of dismissal used by those psychiatrists. The document included an Appendix on "Special issues relating to the treatment of children and young people with ME/CFS: the perspective of parents" by Val Broke-Smith and an open letter to the Chief Medical Officer from Ann Crocker. It also included a recommended reading list.

2001

Submission to the CMO's Working Group on CFS/ME: matters of continuing concern

Margaret Williams 9th March 2001

This 22 page fully referenced document was submitted to the CMO's Working Group (WG) on behalf of the 25% ME Group for the Severely Disabled. Its objective was to gain official recognition of the plight of those who do not fit the Oxford 1991 case definition of "chronic fatigue" drawn up by Wessely School psychiatrists upon which the CMO's WG relied (i.e. those with authentic ME as distinct from psychiatric fatigue), so that ME patients would no longer be excluded from NHS service provision.

The document briefly reviewed the history and symptomatology of ME and noted the physical signs found in ME and it noted the detrimental effect of the term "CFS" caused by its focus on one single symptom, namely "chronic fatigue".

More importantly, because the key players in the CMO's WG were of the belief that subgrouping of the heterogeneous label "CFS" was simply a matter of "semantics", the document provided compelling evidence from international experts of the need for careful subgrouping.

Because the drafts of the CMO's WG Report seemed to totally ignore the available evidence of serious organic pathology in ME/CFS, the document also provided summaries of some of the findings presented at the AACFS Conference in Seattle in January 2001, including evidence of abnormalities seen on brain studies, abnormal neurological findings, visual processing disabilities, biochemical abnormalities, recent virological findings, recent microbiology findings, immunology studies (including evidence of autoimmunity in ME/CFS) and evidence of gene abnormalities, in particular, evidence of prominent RNA not observed in normal controls. Significantly, the prominent RNA bands sequenced showed homology with human genes that are noted for their tendency for gene rearrangement under severe physiologic stress.

The document noted that the practice of medicine ought not to be a pitched battle between patients and their clinicians, and that such a situation might have arisen because for the most part, patients with severe ME are far better informed about their condition than their doctors.

The document was entirely ignored.

Concerns about the forthcoming UK Chief Medical Officer's Report on ME/CFS, notably the intention to advise clinicians that only limited investigations are necessary

Sally Montague Malcolm Hooper 30th July 2001

Because this document placed in the public domain facts that certain members of the CMO's WG apparently would have preferred not to be in the public domain, it caused an outcry from some of the doctors who were acting as Government advisers on the Working Group but who had not declared their competing interests. Of significance was the nature of those undeclared interests: both Professor Simon Wessely and the Medical Adviser to the ME Association (Dr Charles Shepherd) were members of an organisation called HealthWatch (which used to be called The Campaign Against Health Fraud), known for its zealous views which are antagonistic towards alternative and complementary medicine and towards those who believe in environmental and chemically-induced illness, including multiple chemical sensitivity (a well-documented component of authentic ME). It is a campaigning organisation that has in the past accepted money from both the health insurance industry and the pharmaceutical industry. The campaign's own literature states that its aims are to oppose unnecessary treatment for non-existent diseases. Simon Wessely is on record as affirming that ME is a non-existent disease, and between February and April 2002 was involved with a poll of "non-diseases" run amongst doctors by the British Medical Journal: the poll found ME -- along with big ears and freckles -- to be a non-disease that is best left medically untreated. Wessely is listed in HealthWatch documents as a "leading member of the campaign". The Medical Adviser to the ME Association admits to being an active member. Given that the stated remit of the CMO's Working Group was to consider *all* treatment and management options for CFS/ME, for such key figures to be members of an organisation whose members are so strongly opposed to complementary approaches (known to be helpful in ME) seemed a cause for concern.

Also a matter for concern was Wessely's close involvement with PRISMA, a multi-national healthcare company working with medical insurance companies; it arranges "rehabilitation" programmes for those with "CFS" and places heavy emphasis on training sufferers to "regain a normal life again". It claims to have developed a "unique treatment programme" for "hopeless" cases (in which it specifically includes "CFS"). In the PRISMA Company Information, Simon Wessely is listed as a Corporate Officer: he is a member of the Supervisory Board, and in order of seniority he is higher than the Board of Management. It was a cause for concern that his favoured regime of CBT was underpinning every aspect of the draft versions of the Report, so we asked if it was possible that Wessely was recommending to the CMO a management regime for "CFS" that is known to be harmful for those with authentic ME but which is provided by a company of whose Supervisory Board Wessely is a member?

The authors of the document were fiercely attacked for using the pseudonym "Sally Montague", even though no deceit had taken place because the document was never intended for submission to a journal and even though it was explained that "Sally Montague" was a composite name encompassing six different people, including researchers, medical scientists and clinicians, some of whom had a life-time's experience of ME, but who for professional and personal reasons did not wish to reveal their identity, not least because some were themselves severely affected by ME and were too ill to cope with any publicity or media intrusion.

The document contained 89 references, many of which supported our view that investigation is the only way forward towards understanding such a complex disorder as ME, and it set out our concerns about the way the draft versions of the CMO's report continued to ignore the reality and nature of ME/CFS and to assert that only the most basic screening should be carried out for those with ME/CFS. Because of this, the document provided evidence of investigations that international experts in the disorder deemed essential. These included immunological testing; virological screening; endocrine testing; central, autonomic and peripheral nervous system testing; nuclear imaging; tests for vascular dysfunction; lung function testing; testing of exercise capacity; tests for cardiac anomalies; tests for liver dysfunction and ocular testing.

Because of the furore occasioned by the document, on 7th July 2001 the authors released a Statement:

“All six people contributed to the Montague / Hooper paper which sets out their concerns about the forthcoming CMO’s report on CFS/ME. The science described in our paper and the supporting references stand on their own and need no justification. We believe that it is imperative that all the evidence available about CFS/ME is considered before the CMO’s final report is published. Official reports emanating from such a body will have far-reaching consequences which we believe might seriously jeopardise the health and well-being of ME sufferers and render their future prospects very bleak. We strongly reject any attempt to label CFS/ME as a psychiatric disorder for which psychotherapy is the only recommended treatment. It is a matter of personal regret for all of us that it has been necessary to challenge in this way the work of the CMO’s Working Group and its lack of transparency. However, the failure of the CMO’s group to consider all the science and the inability for dissenting views to be accommodated leave us no option”.

(In the event the final Report, as the various drafts, asserted that only the most basic and routine tests were appropriate and that the management regime of choice was to be cognitive behavioural therapy with graded exercise).

Concepts of Accountability?

Sally Montague Malcolm Hooper and associates 28th August 2001

Due entirely to the explosion of harassment directed at Professor Hooper by certain medical members of the CMO’s Working Group and to the torrent of abusive letters to Hooper himself, including a lengthy series of letters to the Vice Chancellor of Hooper’s University demanding that he appear before a “disciplinary” hearing, not forgetting the correspondence from Professor Simon Wessely or the letters sent to Hooper from the Solicitor to HealthWatch, or the letter to Hooper from Nick Ross (of “Crimewatch” fame, who is also one of the founders of HealthWatch but who seemed unaware of what the HealthWatch literature actually states in black and white), it was deemed sensible to compile a comprehensive document setting out the background to the writing of the Montague / Hooper paper.

The document stated that those associated with the Montague / Hooper paper were concerned that UK patients will continue to be denied appropriate investigations if the advice of the “Wessely School” is unquestioningly accepted by the CMO’s Working Group.

The document amounted to 69 pages and contained 134 references. Sections included information on HealthWatch and on its published views about ME: since the late 1980s HealthWatch has carried out a sustained and vicious attack on ME patients, most publicly and notably by its activists Caroline Richmond (a journalist and one of the founders of HealthWatch, known for her extreme animosity towards those with ME) and, even more vitriolically, by Dr Mike Fitzpatrick, a GP named as medical writer for HealthWatch, who also writes for the on-line publication “spiked”. Fitzpatrick is famed for his publications denigrating those with ME and for his public attack in 2002 on the CMO for taking ME seriously, claiming that the CMO’s stance was “a surrender of medical authority to irrationality”. The document also provided some of the antagonistic views of HealthWatch towards nutritional therapies (which have been found to be helpful in ME). The document also noted the involvement of the Medical Adviser to the ME Association with HealthWatch activities against doctors who were deemed by HealthWatch activists to be acting against the best interests of the pharmaceutical industry.

Composite Response on the Final Draft Version of the CMO’s Report of 31st August 2001

Edited by Malcolm Hooper 20th September 2001

This fully referenced 39 page document was a last attempt to modify the intransigent views of the key players who dominated the CMO’s Working Group. It addressed the assertions contained in the final draft of the Report which the international evidence had clearly shown to be untenable and it pointed out glaring and indefensible errors of fact.

The document was once again entirely ignored by those responsible for the CMO’s WG “independent” Report.

The 1996 Strasbourg Convention on Biomedicine and the Reform of the UK Mental Health Act: have they anything to do with the attempt to re-classify ME and CFS as mental illness in the WHO Guide to Mental Health in Primary Care?

Margaret Williams September 2001

This document noted Wessely's view that "Functional somatic syndromes (i.e. psychiatric syndromes, in which he includes "CFS/ME") pose a major challenge to medicine and that they are associated with unnecessary expenditure of medical resources" and his view that such syndromes "urgently require improved management". Mindful of Wessely's beliefs about compulsory "management" of ME/CFS, the document noted the proposed changes to a person's right not to be experimented upon without their informed consent; in particular, that there are three groups of people for whom such consent will not in future be required: those who are deemed to be mentally ill; those for whom no other known treatment is effective, and children. It also noted that in certain situations, "general interests" will take priority over those of the individual. It considered the proposals for reform of the UK Mental Health Act (1983), which would give psychiatrists far greater powers to enforce compulsory psychiatric treatment upon both adults and children in that psychiatrists would be able to drug people (including children against the wishes of their parents) if they have "any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment of mental functioning", and the document noted that this seemed a chillingly watertight definition. The document questioned how such changes might relate to those with ME/CFS if Wessely et al were to be successful in re-classifying it from its present classification of neurological to a "mental" classification, and it included a quotation from a Ministerial response to this question. The document also questioned whether "general interests" are already taking priority over those of the individual, and asked if those "general interests" are economically and commercially determined.

Comments on the Australasian Report on CFS

Margaret Williams (compiled from various published critiques). 2nd December 2001

"Wessely School" influence is not limited to the UK: it extends to Australasia, where Wessely has certainly lectured; see "Simon Wessely: Prophet or Profit" by Dr Ken Jolly, a New Zealand GP, published in ANZMES Meeting Place: Spring 1998: 56:10-12, where Jolly exposes what he refers to as "an alarming trend" by Wessely of diverting research into ME along blind paths; how this has affected sufferers' accessibility to medical care and financial assistance and how Wessely's influence has resulted in clinicians with opposing views being sidelined by his having convinced the authorities that ME patients do not have a physical illness. Jolly highlights what he calls Wessely's "main mistake", namely that Wessely concentrates only on "fatigue" and ignores all other symptoms, thereby distorting study results, noting that Wessely's beliefs are misguided, but that Wessely may be unaware of the damage he is causing to sufferers. There is one particularly prominent psychiatrist in Australia and another in New Zealand who seem to display an identical closed mind to the international scientific evidence of organic pathology in ME/CFS and who seem to exhibit the same bias as shown by Wessely himself. The Report of The Royal Australasian College of Physicians reflects this psychiatric bias.

Because the psychiatrists who dominated the CMO's Working Group and the MRC CFS Research Advisory Group placed such heavy reliance upon the Australasian Report, it became necessary to compile a concise document containing published critiques by experts including Dr Abhijit Chaudhuri from Scotland; Dr Eleanor Stein from Canada; Dr Peter del Fante from Australia; Professor Peter Rowe from Johns Hopkins, Baltimore; Dr Lawrence Budd from Australia and Dr Nicole Phillips from Australia, all of whom cogently exposed the many shortcomings and undisputed psychiatric bias of the Australian Report.

What is ME? What is CFS? Information for Clinicians and Lawyers

EP Marshall M Williams M Hooper December 2001

This fully referenced document was published as a 26 page booklet and because of the demand, went through four print runs. It looked at the history and classification of ME; it provided a description of ME; it documented the symptoms seen in ME and the evidence of abnormalities found in ME; it listed precipitating factors and the physical signs found in ME; it discussed the changing definitions in relation to the emergence of "CFS" in 1988, and at how "CFS" displaced ME in the UK. It included a note of caution for lawyers and suggested that clinicians and lawyers need to come to their own

conclusions about what might motivate a group of doctors (mostly psychiatrists) to disassemble a formally classified neurological disorder and endeavour to replace it by a much larger category of “behavioural” illness.

2002

Medical Research Council’s plans for research

Margaret Williams 18th June 2002

Following the publication in January 2002 of the CMO’s Working Group Report on “CFS/ME” and the decision by the Chief Medical Officer to hand over responsibility for the direction of future research into “CFS/ME” to the Medical Research Council, a Briefing on the MRC’s strategy for advancing research into CFS/ME took place at the House of Commons, at which Dr Diana Dunstan of the MRC announced that a group of leading experts from various fields had been convened “who did not previously specialise in CFS/ME” because it was felt important to have “a fresh and independent look” at the issue.

This document noted that it would seem to be erroneous for the MRC spokesperson Dr Diana Dunstan to claim that members of the panel were “independent” and “fresh” to the issue of ME/CFS and that it would seem to be deliberate misinformation, and thus misleading and untrue. It was pointed out that at least two of the MRC Research Advisory Group (RAG) members were not at all “fresh” to the issue, because one of them (Professor Alan McGregor) had not only co-authored two papers on CFS with Wessely but was listed as a member of the Linbury Trust Advisory Panel on CFS that had been funding Wessely’s psychiatric studies on “CFS” since 1991; another (Professor Philip Cowan from the Psychopharmacology Research Unit at Oxford) was on record as holding strong views on the psychiatric nature of CFS and was co-author of a paper on CFS with Professor Michael Sharpe. It was also noted that another member of the RAG was Professor Til Wykes (who, as Simon Wessely, is from The Institute of Psychiatry) who is on record as believing about CBT: “If you encourage them to do things, as part of a treatment called cognitive behavioural therapy, you do see improvement. It’s a way of getting people to take control of their lives”.

The document asked why there was no neurologist and no vascular medicine specialist on the MRC panel of “experts”.

Following representations, the then Chief Executive of the MRC (Professor Sir George Radda CBE FRS) was compelled by letter dated 15th July 2002 to concede Professor McGregor’s involvement with the Linbury Trust and the fact that he had previously co-authored papers on CFS with Wessely (which Radda inadequately tried to defend, saying “You cite papers from some years ago but he has not published further on CFS/ME”). However, the letter also stated: “Thank you for your suggestion about the need for a neurologist. This fits with other comments we have received. The Chairman of the group agrees this is a good idea and we are actively seeking a suitable person”. The inclusion of a suitable neurologist ought surely to have been obligatory from the outset in a group that was supposed to be considering future research for a WHO-classified neurological disorder.

Over-view of the Alison Hunter Memorial Foundation ME/CFS Clinical and Scientific Meeting, December 2001, Sydney, Australia

Margaret Williams (with grateful acknowledgement to Dr Rosamund Vallings and to Jan van Roijen)
15th July 2002

This document summarised some of the presentations given at this international conference by world-renowned experts including Anthony Komaroff, Professor of Medicine at Harvard; Professor Kenny de Meirleir from Brussels; Professor Neil McGregor from Newcastle, New South Wales; Dr Dharam Ablashi from Colorado and Dr Susan Levine from New York, who variously presented evidence on the biology of ME/CFS; on gastrointestinal problems and gastric emptying studies; on ME and MS as subsets of a group of cellular immunity disorders; on active HHV6 infection and its correlation with RNaseL low molecular weight protein (37KDa) in ME patients; on the objective evidence of brain impairment; on disruption to regional cerebral blood flow; on the pathophysiological mechanisms in ME; on the biochemical anomalies found in ME; on food intolerance in ME and on channelopathy in

ME. Komaroff emphasised that some patients are completely disabled by ME and noted that their impairment, as measured by the SF-36 instrument, is comparable with that of patients with congestive heart failure. He said the evidence indicates an organic basis for the disorder.

Important paper which explains multiple chemical sensitivity (MCS).

Reviewed by Margaret Williams August 2002

This document reviews a seminal paper by Professor Marty Pall from the School of Molecular Biosciences at Washington State University published in the prestigious Journal of the Federation of American Societies for Experimental Biology in September 2002.

Pall's paper presents a validated explanation for the biological basis of the specific symptom pattern found in MCS (including the 'spreading phenomenon') associated with chemical exposure and injury. MCS is a known component of ME. Sceptics, including psychiatrists, have been wont to scoff at MCS sufferers, claiming that "there is no known mechanism whereby low levels of chemicals of widely varied chemical structure can interact adversely with numerous organ systems"; thanks to Pall, such disbelief and dismissal will no longer be tenable.

Notes on current research in ME

Margaret Williams November 2002

This document noted that the key feature of current ME research is one of compromised immune cells, with significant disturbance to various important pathways and it noted the work of three teams.

The team from the Vascular Diseases Research Unit at Dundee (Dr Vance Spence et al) have identified four major pathways that are deranged in ME: the pattern of results is specific to ME and the evidence points towards ME being a separate and distinct syndrome. Many of the symptoms of ME can be explained by dysfunction of blood vessels, especially at the level of endothelial cells (the inner lining of blood vessels). There is clear evidence of accelerated apoptosis (programmed cell death) of specific immune cells in ME patients.

Professor Kenny de Meirleir from Brussels presented a paper in Northern Ireland on 2nd November 2002 in which he demonstrated that ME is a disorder of the immune system: he has found evidence of small fragments of specific RNaseL nucleotides (from the antiviral defence pathway) within the cells, causing chaos, with serious injury to the cell. The damage caused by these fragments is not discernible on standard blood tests. Such interference gives rise to disturbances in many pathways including oxidative stress, lipid peroxidation and cellular apoptosis, with consequences for the vascular endothelium. This work ties in with the work of Spence et al.

Professor Mina Behan of Glasgow (now deceased) had found very swollen muscle cells in some patients with well-defined ME, the cells being disordered and dysfunctional, with clearly visible enlarged and thickened mitochondria. This hypertrophy of the mitochondria is possibly the result of the cells' continued efforts to get energy.

The document noted that given these known biomarkers of significant cell injury in ME, for the authors of the CMO's Report to advise that comprehensive testing is neither necessary nor appropriate for those with ME and for the Report to promote forced exercise regimes (with the assertion that psychotherapy is the only "evidence-based" form of management for ME) has once again been shown to defy scientific credibility.

Response to the MRC Research Advisory Group (RAG) Draft Document for Public Consultation on "CFS/ME" Research Strategy dated 17th December 2002

M Hooper EP Marshall M Williams 27th December 2002

This 26 page document containing 37 references was submitted to the MRC as part of the MRC's "public consultation". It contained stringent refutations of the many misleading assertions contained in the RAG document, for example, the RAG document stated at paragraph 6: "A strategy is proposed

which reflects the current state of knowledge of CFS/ME”, which was demonstrably untrue because the RAG also stated (at paragraph 82) that “The MRC CFS/ME Research Advisory Group has not undertaken a detailed review of the current level of scientific knowledge of CFS/ME” and (at paragraph 102) stated “at no point has the literature been systematically reviewed”, so our document pointed out that this was surely essential if the RAG wished to produce a credible research strategy. Another misleading assertion in the RAG document stated: “Clinical experience would indicate that most patients with CFS/ME have neurological signs that lie within the normal range”, so we drew attention to the fact that both the 1991 Oxford criteria for CFS and the 1994 CDC criteria for CFS expressly exclude patients who have any physical signs and that the 1994 criteria are unequivocal on this, stating: “We dropped all physical signs”. We asked what disorder the RAG was talking about as it could not be talking about ME, which is formally classified by the WHO as a neurological disorder. The RAG consultation document went on to emphasise the effects of suggestibility on patients with CFS/ME and it also emphasised “personality factors”, which we pointed out seemed to expose the underlying agenda of the MRC, so we again disputed that the RAG was aware of the current state of the biomedical knowledge on ME/CFS and suggested that without such knowledge, it was not possible for the RAG to deliver any credible research strategy for ME/CFS.

In our document, we said: “The authors of the RAG draft document have ignored all the justified criticism of the information on which they place so much reliance; this is momentous, because that criticism revealed the misrepresentations, the misinterpretations, the denial of available credible evidence, the deception, the selectivity in use of the available evidence, the methodological flaws and the many omissions which pervade so much of the Wessely School literature. Significantly, claims made by these psychiatrists are not established facts at all, nor are they supported in the international literature”.

We asked if there was a credible explanation, and suggested one that seemed to have most validity – namely, a contribution from Professor Michael Sharpe contained in a Report of the largest medical insurance company (UNUMProvident --- for Sharpe’s involvement with this company, see below) called Trends in Health and Disability 2002, in which Sharpe said about CFS: “There is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are patients’ beliefs and fears about their symptoms. Causal factors are personality, disease attribution and avoidant coping style. Obstacles to recovery (are) the current system of state benefits (and) insurance payments. It will be imperative that health and social policy address this problem. Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue”.

In our conclusion we said that bad science, bad “policy” and vested commercial interests deserve to be exposed and criticised, but it seems likely from the MRC RAG document that a substantial number of very sick people with a complex neuro-endocrine-immuno-vascular disorder are not going to be allowed to stand in the way of those commercial interests.

(It is important to be aware that in 2000 [during the life of the CMO’s Working Group], the parent of an ME adolescent believed it vital that all members of the CMO’s Key Group and Children’s Group should each have a copy of Dr Byron Hyde’s 724 page seminal textbook on ME/CFS, so at her own expense she arranged for 128 copies to be shipped over from Canada direct to the Department of Health’s Headquarters Disability Section at Quarry House in Leeds. It cost her £800. She herself arranged that out of the 128 copies, twenty would be sent to the members of the CMO’s Key and Children’s Groups, which Helen Wiggins at the Department of Health in Leeds promised to do. On 27th November 2003, Dr Charles Shepherd [Medical Adviser to the ME Association and member of the CMO’s Key Group] confirmed in writing that: “20 copies of Byron’s book may well have been intended to go to members of the CMO’s Key and Children’s group but I never received one. And I’m almost certain that nobody else on either of these two groups did either”. The failure to provide the promised copies of this important textbook was but a fore-runner of what occurred during the life of the MRC Research Advisory Group: the person who had paid for the copies to be sent to the Department of Health had been informed that, of the original 128 copies, the remaining 108 would definitely be put to good and appropriate use, so when problems with the MRC RAG arose, she contacted Quarry Hill to arrange for copies to be sent to each of the RAG members. Having managed to obtain the names and email addresses of every member of the RAG, she contacted each of them to advise them that they would be receiving a copy of the textbook. What happened next is astonishing: the RAG members contacted Elizabeth Mitchell of the MRC about the book, who rang the parent of the sick youth and

was very angry indeed, refusing outright to allow each member of the RAG to see a copy. On 20th October 2002, all Elizabeth Mitchell would agree to was that TWO copies could be sent from the Department of Health in Leeds to the MRC (which she insisted was to be at the parent's own expense). When the parent contacted Quarry House in Leeds, she was told that the Department of Health had "lost track" of the remaining 108 textbooks. The parent managed to establish that some had been dumped at the Cystic Fibrosis Service at Seacroft Hospital in Leeds, but that most of the 108 books were missing, believed trashed. On 8th January 2003 the parent was informed by Elizabeth Mitchell that she would allow the two copies to be available to RAG members before and after one meeting only, and that this was sufficient. It seems unrealistic to expect each member of a group of busy people to be able to consider a 724 page textbook if it was available to them for only a few minutes before and after one meeting).

2003

Note on the apparent bias of MRC "CFS/ME" Research Advisory Group in their draft document for public consultation dated 17th December 2002

M Hooper EP Marshall M Williams 2nd January 2003

In this short document, entitled "**Elementary Rules of Procedure**", we noted that there are in existence such rules, of which the MRC RAG seemed to be ignorant. We noted that the MRC RAG consisted of experts of professorial status, so they would be expected to know that post-graduate students who undertake a higher degree by research are expected before proceeding to define the proposed topic and to produce a comprehensive review of the relevant literature. Only by doing so can they place themselves in a position to ensure that their own prospective contribution represents a useful development of knowledge. We posited that what seemed to be missing from the MRC RAG draft document was the prerequisite review of *what has already been established about the disorder*.

We noted that by neglecting this first step, the RAG members failed to ensure that their contribution would be situated squarely on the foundations of existing knowledge about the disorder, and we noted that as the pre-existing body of knowledge is extensive, it appeared to have been deliberately ignored by the MRC RAG, and that by proceeding as if this substantive body of mainstream knowledge did not exist, the authors of the RAG Report laid themselves open to suspicions of disingenuousness, or even frank intellectual dishonesty. We commented that any conscientious academic supervisor would be obliged to reject the MRC proposal on the grounds that the proposed research strategy would not be expected to move understanding or knowledge along, but would only reinforce existing confusion. We noted that it was both disappointing and baffling that the MRC had allowed such a poorly-grounded, haphazard and potentially biased proposal to be entertained.

We received no acknowledgement from the MRC and our communication was ignored.

Some salient points arising from the AACFS 6th International Conference which the MRC RAG might wish to consider

Margaret Williams 3rd March 2003

The document summarised some of the findings at the AACFS International Conference that was held at Chantilly, Virginia, USA from 31st January to 2nd February 2003. As with the preceding document, it was submitted to the MRC but was ignored.

The document noted that in their Introduction and Overview, Professor Charles Lapp (from North Carolina) and Professor Leonard Jason (from Chicago, Illinois) stated that in 50% of ME/CFS cases there was a family history of autoimmune disease and that people with ME/CFS were found to be more impaired than those with Type 2 diabetes, congestive heart failure, MS, or end-stage renal failure; there may be abnormal laboratory findings including immune complexes, atypical lymphocytes, lowered IgG, and anomalies in cholesterol, anti-nuclear antibodies and thyroid antibodies. SPECT scans demonstrate decreases in cerebral blood flow with exercise; up to 50% of patients are unable to work.

The document noted that Professor Robert Suhadolnick (Temple University, Philadelphia) gave an overview of the biochemistry and genetics of ME/CFS and confirmed that immune activation and NK cell decrease are evident in most patients. He confirmed that 2-5 RNaseL abnormalities have been shown in ME/CFS patients, particularly the severely ill, but not in healthy controls, and that elevated levels of RNaseL are associated with reduced maximum oxygen uptake and with exercise duration. He also showed that there was an increase in markers of oxidative damage and that there is evidence of changes in brain function.

The document briefly summarised other presentations: John Hay (from Buffalo, New York) presented evidence of infection and immunological changes, and noted the autoimmunity link in ME/CFS; K Maher (from Miami, Florida) discussed the molecular defects seen in ME/CFS; P McGaffney (from Minneapolis, Minnesota) demonstrated a significant difference in gene expression, showing elevated expression of IL-1 (a very potent inflammatory cytokine) and noted that certain genes were dysregulated in almost all ME/CFS patients but in none of the controls; Dr Daniel Peterson (from Incline Village, Nevada) showed abnormalities that included altered HPA axis, regional hypoperfusion in the brain, hypo brain metabolism, autonomic dysfunction and perturbation of brain hormones, as well as either primary or reactivated central nervous system infection.

Professor Ben Natelson (from New Jersey) showed that 44% of those with ME/CFS were found to have lumbar puncture results in the abnormal range for protein or white blood cells (thus supporting the view that some patients do have underlying pathologic brain processes that are responsible for their symptoms); Dr Christopher Snell (from Stockton, California) presented evidence of an abnormal response to exercise in ME/CFS patients; Dr Arnold Peckerman (from Newark, New Jersey) presented evidence of inefficient utilisation of respiratory muscles, and E Georgiades (from Glasgow, UK) had examined the cardiopulmonary and metabolic responses to exercise in ME/CFS patients compared with controls and reported that patients demonstrated impaired exercise tolerance.

As noted above, as with all our submissions to the MRC, our document was ignored.

Matters for the MRC RAG on “CFS/ME” to consider

Margaret Williams 6th March 2003

Before the publication of the final MRC RAG Report, two further points were brought specifically to the attention of the MRC RAG:

1. At the American Association of CFS (AACFS) 6th International Conference in 2003, Professor Charles Lapp drew attention to the fact that Dr Daniel Clauw (Director of the Fatigue Research Centre at the University of Michigan) had studied the effects of CBT on over 1,000 patients and found that after three months, there were very modest improvements, but when followed up at six and twelve months, those modest gains were lost.
2. On 2nd March 2003, the Sunday Times reported that under the auspices of the Cochrane Collaboration, Simon Wessely had just led a review of the evidence for psychological counselling and that the Cochrane review concluded that such counselling was at best useless and at worst made people worse.

The question posed to the MRC was explicit: if counselling does not work, and if the aim of CBT is to counsel patients with ME/CFS about changing their beliefs and if, as shown by Clauw, CBT has no lasting benefit, on what ‘evidence-base’ will the MRC continue to grant £2.6 million to psychiatrists of the Wessely School to keep on looking at interventions that have already been shown not to work?

Short Review of New Publication by Professor Malcolm Hooper

Margaret Williams 4th April 2003

This document noted that two new publications would be of paramount importance to both the Gulf War Veterans and the ME community: a news release by Robert Bradford, Senior Director of Communications at the Salk Institute, California, drew attention to published findings from the Salk

Institute for Biological Studies at La Jolla, which was the first to demonstrate a clear genetic link between neurological disorders and exposure to organophosphate chemicals.

The second publication was a colour-illustrated fully referenced 85 page booklet by Professor Malcolm Hooper called “Engaging with Myalgic Encephalomyelitis”. In his customary robust form, Hooper deals with facts, not beliefs or speculation, and those facts are soundly based on biochemistry, which those who promote a primary psychiatric pathoaetiology will find difficult to refute with any degree of credibility. Hooper is explicit: he writes that he has examined much of the ME literature and is “fully persuaded of the organic nature of this illness and the folly and cruelty of attempting to regard it otherwise”.

Hooper is unenthusiastic about the MRC RAG Report, stating that “much evidence was ignored” and he quotes the searing comments of world experts who pointed out that the Royal Australasian College of Physicians’ Guidelines upon which the MRC RAG relied were heavily flawed, biased, inaccurate and based on personal belief as opposed to evidence-based science.

He identifies various investigations, including more specialised tests than the basic screening advocated by the CMO’s Working Group Report, which are of major importance in diagnosis, together with treatment protocols that have a realistic prospect of success, including the removal from the diet of casomorphins (present in cows milk) and gliadomorphins (present in wheat).

The main thrust of the booklet is a detailed explanation of the neuroendocrine – immune paradigm and the interactive web of biochemical / physiological deficits found in ME patients, and it explained the mechanism by which chemicals cause changes that allow free transport of compounds into areas such as the brain and central nervous system from which they would normally be excluded and how they are then absorbed into the blood stream, giving rise to autoimmune diseases with very significant and chronic damage to health.

Ignoring the evidence? A response to the final version of the MRC CFS/ME Research Advisory Group Strategy Report of 1st May 2003

Malcolm Hooper Eileen Marshall Margaret Williams 5th May 2003

Our concerns that without an adequate understanding of the underlying pathology of ME/CFS there could be no advance in the search for possible treatment were disregarded and all our documents were entirely ignored: the final RAG report that was released on 1st May 2003 accepted Wessely School psychiatrists’ conjecture about the disorder in preference to a biomedical explanation, of which evidence there was a sustained rejection throughout the RAG Report.

The RAG Report stated that it fully endorsed the conclusions of CMO’s Working Group Report; it asserted that studies of causal pathways of ME would do nothing to increase understanding of the disorder and it recommended CBT and graded exercise for those with “CFS/ME” and, specifically, that more studies of CBT and graded exercise should be undertaken, and that the direction of future management strategy should “concentrate on the effects of these interventions across the spectrum of the disorder” (i.e. on both the least severe and on the most severe cases).

Of particular note was the fact that the Report’s author was Dr Chris Watkins, whose title was “MRC Programme Manager for Research on Mental Illness”.

In our document, we recorded our specific concerns about the misinformation contained in the MRC RAG Report and drew attention to the apparently deliberate failure to confirm the WHO classification of ME as a neurological disorder (which exactly echoed the misinformation in the CMO’s Working Group Report of January 2002).

We noted that no-one denies the reality of psychiatric illness, nor the debility such psychiatric illness may cause, but what is at issue here is **accuracy of case definition**, which in our view has not been helped by the MRC RAG Report: whereas psychiatric illness is commonly amenable to psychotherapeutic interventions, complex neuro-immune disorders are not.

As was the case with the MRC's initial Briefing about the need for "fresh" experts, the MRC once again seemed less than transparent about the Report itself, ensuring that the "take-home" message for the media about their RAG Report was that the MRC intended to make "CFS/ME" a priority area for grants.

What it failed to disclose was that its preference was for grants to psychiatrists of the Wessely School: just two weeks after the release of the RAG Report, on 15th May 2003 it became known that the MRC was to fund two trials of CBT for those with "CFS/ME" at a cost to the taxpayer of £2.6 million (the PACE trials, an acronym for active Pacing, graded Activity, Cognitive behavioural therapy and Evaluation).

This was preceded by an announcement on 12th May 2003 by the Health Minister (Jacqui Smith) that an additional £8.5 million was being made available by Government for services for those with "CFS/ME".

It quickly became obvious that these "services" are in fact clinics that will deliver CBT and graded exercise: job description advertisements for staff for these clinics stated that the aim is to "change perpetuating illness behaviour and modify predisposing personality style" for patients who "experience barriers to understanding" and stated "there can be significant barriers to accepting the changes needed in behaviour, which have to be overcome in therapy". Significantly, the job descriptions also stated that for patients with CFS/ME, "**medical intervention is no longer appropriate**" and the service is extended to patients who have **mental health problems**; the post-holder is expected to "raise awareness of the approach adopted by the new centres to GPs and other local service providers".

That would seem to be blatant proselytising for ME/CFS to be regarded as a mental disorder.

ME is suffering from inaccurate diagnosis

Janice Storey and Margaret Williams.

Biologist: June 2003:50: (3):104

This item in the "Letterbox" section of the *Biologist* stressed the need for accurate diagnosis and classification in ME; it drew attention to the published international evidence of a variety of biomarkers for the disorder and highlighted the fact that certain UK grant-awarding bodies are ignoring the large body of evidence of organic pathology in ME, preferring to allocate research funding to re-evaluate psychological management strategies that are more appropriate to aberrant illness belief.

Notes on the involvement of Wessely et al with the Insurance Industry and how they deal with ME/CFS claims

Margaret Williams 17th June 2003

This referenced 21 page document considers the disastrous situation in relation to ME/CFS claims and the insurance industry: it provides evidence of the involvement of psychiatrists of the Wessely School as well as demonstrating the effects of this involvement on those with ME.

In the document, we noted that when an MP requires information about ME/CFS, s/he usually turns to the House of Commons Library; however, it is known that an MP is often provided with information that is selected by House of Commons Library staff and a survey showed that MPs are provided **only** with information endorsing a psychiatric aetiology (even though books, journals and international conference reports etc that demonstrate the organic nature of the disorder are known to have been placed in the Library for the use of MPs, including Dr Byron Hyde's 724 page textbook). When the reason for this selectivity was legitimately queried, an MP's constituent received an angry and intimidating letter from the Head of the House of Commons Library. We noted that this seemed to indicate the immediate State / Government response when people dare to ask how an MP is provided with information about ME/CFS. The same control of information seems to apply to the House of Lords, because a peer has ascertained that the information supporting an organic basis for ME/CFS has been removed to the Library archives, so is not available unless specifically requested. Unless people know what is in the archives by name, it is difficult for them to request such information.

The document contains Appendices that set out actual case histories of individuals' struggles with their insurers, including hard evidence of the coercion tactics used by insurers to force claimants to be seen by Wessely School psychiatrists, particularly Professor Michael Sharpe himself.

A further Appendix contains quotations from the published works and spoken views of Professor Michael Sharpe on the subject of ME/CFS (see below).

Spin Wins?

Margaret Williams 26th July 2003

This short document noted that that MRC had openly declared its hand by categorically asserting (quote): "CFS/ME does not refer to a specific diagnosis". I noted that the undifferentiated term "CFS" is an umbrella term that encompasses many disorders that are not ME (one such disorder being medically unexplained fatigue, which has no resemblance to ME), and it asked the MRC on what evidence it over-ruled the WHO classification of ME as a neurological disorder. It noted that it is not sufficient for the spinners at the MRC to claim that ME is nothing more than collusion between suggestible patients and naïve doctors who accept that such patients have a severe physical illness because the evidence is there for all to see, including the evidence that ME can be induced both by viruses (as in past epidemics) and by chemicals, and that its incidence is spiralling out of control.

The document noted that "spin" itself is now spinning out of control, because as far as ME is concerned, it is rampant throughout UK medicine, thanks to the unremitting efforts of certain psychiatrists who have indisputable links to the insurance and pharmaceutical industries, industries which stand to gain financially from the imposition of psychological regimes of CBT, graded exercise and antidepressants upon ME patients, many of whom are already at the limits of their endurance, but who are left in no doubt whatever that if they do not comply, their benefits will be stopped, either by the State or by their insurance company (and the financial gains of the psychiatrists themselves should not be forgotten either, for they are known to act as medical advisers to insurance companies that include UNUM, Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life, Permanent Insurance, and the massive re-insurer Swiss Re).

The document noted that for the spinners who control Government policy on ME to continue to deliberately harm such people by denying the existing evidence of biomarkers of serious organic pathoetiology shows that the spinners can have no morality, compassion, decency, integrity or humanity.

The views of the Medical Research Council on ME/CFS peer-reviewed publications

Margaret Williams 27th September 2003

Following an article on 27th September 2003 by Jerome Burne in the Times that questioned the MRC RAG Report's recommendations, our document drew renewed attention to one of the more fallacious claims contained in the MRC RAG Report, which stated that findings in the biological area of CFS/ME are generally "not published in the peer-reviewed literature", nor are such articles "well-described".

In our response to the MRC RAG draft document for public consultation, we had listed 65 mainstream (mostly peer-reviewed) journals that had all published important biomedical evidence in relation to ME: those prestigious journals include some with a high impact factor, such as Nature, which has an impact factor of 29, and the New England Journal of Medicine, which also has an impact factor of 29. (In science and medicine, journals are allocated an "impact factor"; as a general rule, journals with a high impact factor are amongst the most prestigious and are relied upon by funding bodies and policy-makers). Other journals we listed included JAMA, Annals of Internal Medicine, Reviews of Infectious Diseases, CRC Critical Reviews in Neurobiology, Archives of Internal Medicine, Quarterly Journal of Medicine and many more, thus exposing the erroneous and infantile assertions of the MRC RAG Report.

The document was ignored, just as our original submission as part of the MRC "consultation process" had been ignored.

The Mental Health Movement: Persecution of Patients? Briefing Paper for the House of Commons Select Health Committee

Document prepared for the Countess of Mar by Professor Malcolm Hooper, in collaboration with members of the ME community. December 2003

This comprehensively referenced 75 page spiral bound volume was prepared for the House of Commons Health Select Committee which, following a meeting on 24th March 2004 of its then Chairman (David Hinchliffe MP) with the Countess of Mar, was to have considered the whole issue of ME/CFS: at that meeting, Hinchliffe had shown himself to be appalled at the situation and seemed very keen to take the matter forward via his Committee, promising in person that this would happen and that he would take advice, but just a few days later, someone (not Hinchliffe himself) contacted Lady Mar to say that it would not be possible for the Select Health Committee to consider the issue of ME/CFS.

The prepared document asked if it is the case, as demonstrated in a recent TV documentary, that multi-national corporations and not governments now rule the world, and if powerful and influential psychiatrists who work within the Mental Health Movement are linked to these corporations that now dominate and control medical and research institutions and whose life-blood is profit?

The document presented evidence to show that:

- In the UK, patients with ME/CFS, particularly children, have suffered gross and barbaric abuse and persistent denigration as a consequence of the beliefs of certain psychiatrists who are attempting to control the national agenda for this complex and severe neuro-immunological disorder, who by their words and deeds have wreaked havoc in the lives of ME/CFS patients by their arrogant pursuit of a psychiatric construct that ignores the abundant scientific and medical evidence of organic pathology
- There have been persistent and frequently covert attempts by these psychiatrists to subvert the international classification of ME/CFS from neurological to psychiatric, with destructive consequences for those affected
- These psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to Government Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support for those with ME/CFS
- Influenced by these psychiatrists, Government bodies such as the MRC have continued to propagate the same falsehoods, with the result that patients are left without any hope of appropriate health service provision or delivery.

The document asked the Select Health Committee to address two specific questions: (i) is the Department of Health's current and proposed policy on the management of ME/CFS as provided and promoted by psychiatrists of the Wessely School harmful to patients and (ii) are such patients being abused as a consequence of scientific misconduct?

It pointed out that merely to state that there is "medical disagreement" over ME/CFS is not enough, as people with power are misusing that power against sick and vulnerable people and are using it to further their own vested interests, and that no-one in authority is listening.

The document spelled out the tactics of denial used by Wessely School psychiatrists, demonstrating especially how the denial is directed at undermining the expertise of doctors who hold different views about ME/CFS from themselves, and how the deniers apply a double standard to the evidence – they support their own claims with a select choice of studies that have been shown in the medical literature to be flawed, whilst insisting that those who oppose them provide irrefutable proof of an organic pathology (which when provided, they simply ignore).

The document provided two Appendices containing quotations from the published works of Professor Simon Wessely and Professor Michael Sharpe on ME/CFS, those from Wessely's works covering the period from 1988 to 2003 and those from Sharpe covering the period from 1991 to 2000, the latter including Sharpe's better-known quotations, for example: "psychiatric management may be defined as

treatment of the mentally ill”; “viral infection is of theoretical interest but of minor importance”; “personality factors (attitudes, beliefs, thoughts) and behaviour have been shown to perpetuate disability. These dysfunctional cognitions include the beliefs that recovery is not under personal control”; “the exclusion of persons (with psychiatric disorders) would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illness”; “evidence for the superiority of CBT is in keeping with the evidence that the perpetuation of unexplained somatic symptoms is best understood in terms of psychological factors (such as) misinterpretation of bodily sensations and unhelpful coping behaviour”; “(patients’) beliefs are targets for therapeutic interventions”; “many physicians are reluctant to make the diagnosis of CFS (because of) reinforcing unhelpful illness beliefs”; “patients need a diagnosis in order to organise their dealings with the world of benefits”; “CFS may serve as a culturally defined function which allows a socially acceptable expression of distress”; “referral to ‘specialists’ should be avoided as they can entrench illness behaviour” (presumably Sharpe here excludes referrals to psychiatrists).

Sharpe is known to have recommended to medical insurance companies that claimants with ME/CFS should be subjects of covert video surveillance, whilst in its “Chronic Fatigue Syndrome Management Plan”, the insurance company UNUM (with which Sharpe is closely involved) proclaims about “CFS”: “DIAGNOSIS: neurosis with a new banner”.

Sharpe is also known to have received many letters from ME/CFS patients themselves, as well as from their despairing carers, to one of whom he replied on 25th April 2000: “Whilst I understand your desire to have the condition classified as a Neurological Disorder, as I said previously I am not convinced this is in fact the best strategy. This is because trying to change doctor’s behaviour (*sic*) by altering classifications probably will not work and might even provoke a paradoxical response. I suspect that (your tactics) are as likely to backfire as to further the cause of obtaining better treatment for patients”.

This response from Sharpe is curious, given that ME has been formally classified as a neurological disorder since 1969, a fact of which this influential “expert” seemed to be unaware.

The document pointed out that as with Wessely, it is not just a matter of noting the more offensive statements but rather it is the relentlessness of the same message over and over again, and the fact that the message does not adapt to – but actively dismisses – the strength of emerging biological evidence which shows these psychiatrists to be out of touch with international scientific knowledge about the disorder.

2004

Comparison of MRC-funded research and MERGE-funded research into ME/CFS

Margaret Williams 20th March 2004

This document briefly compared the usefulness of the psychosocial studies of CBT that are to be funded by £2.6 million with the outstanding work that the small charity MERGE (ME Research Group) has successfully funded from donations, noting about the former that the 25% ME Group for the Severely Affected stated “there is little or no evidence to support the claim that ME patients will benefit from the highly controversial and hotly contested psychological treatment strategies”.

By comparison, MERGE is dedicated to biomedical research into the causes, consequences and treatment of ME, and despite being desperately short of funding has already achieved far more in furthering the understanding of ME/CFS since its inception in 2000 than the MRC has achieved in the last 20 years.

Our document summarised MERGE’s presentations at a Royal Society of Edinburgh Workshop held on 3rd October 2003:

Everyday in the UK, between 120,000 and 240,000 people waken with debilitating malaise and pain; they remain ill and largely ignored by mainstream medicine. Graded exercise therapy is not universally successful in ME/CFS. The human cost of ME is substantial and has not been well reported. A range of abnormalities has been found in ME by a number of different research groups (biochemical, vascular, brain and muscle). The microvascular research laboratory at Dundee has demonstrated that

the vascular response in ME is very unusual and is unlike any other diseases encountered. There may be re-perfusion injury in ME patients (a state where the vasodilatation that is necessary for the delivery of nutrients is compromised). Vascular symptoms characterise ME and data show that arterial stiffening is increased in some patients with ME. Blood vessels of patients with ME have been shown to be abnormally sensitive to acetylcholine, a most unusual if not unique situation. The central hypothesis is that there is endothelial dysfunction in ME: circulating levels of endothelin-1 (one of the most powerful vasoconstrictors) have been shown to be raised in people with ME (high levels have been reported in myocardial infarction, in diabetes and in HIV infection). The symptoms of post-exertional myalgia in ME may be akin to those experienced by the vascular patients with intermittent claudication. **These findings are suggestive of an underlying viral or toxic illness associated with persistent infection and immune activation.**

The document asked what possible justification can the MRC and Government have for continuing to ignore the pleas for funding research into the biomedical aspects of ME/CFS, whilst continuing to fund yet more psychiatric “research”, the aim of which seems to be to deny the organic nature of such a uniquely complex organic disorder.

Some questions about ME/CFS to which credible answers are urgently required

Malcolm Hooper Margaret Williams 22nd March 2004

This document was prepared for the Countess of Mar’s various meetings with the Chief Executive of the MRC (Professor Colin Blakemore), MPs and Ministers; it set out the many problems with the CMO’s Working Group on “CFS/ME”, as well as problems with the MRC and with NICE (National Institute for Clinical Excellence, whom both the CMO and the MRC have asked to develop clinical guidelines for the diagnosis and management of “CFS/ME”).

In relation to the MRC, the document asked how the MRC can possibly justify the granting of millions of pounds sterling to Wessely School psychiatrists, given that their work has been universally shown to be flawed, and given also that they themselves concede that for those with ME/CFS who have taken part in their trials of CBT and graded exercise, there is no lasting benefit at follow-up.

It asked how the MRC could be unconcerned that the PACE trials run by Professors Peter White, Michael Sharpe and Simon Wessely are to use the Oxford 1991 (psychiatric) criteria for “CFS”, given that those criteria have been shown to have no predictive validity and have never been adopted internationally and, most importantly, when they specifically include those with chronic fatigue due to psychiatric disorders and specifically exclude those with any neurological signs (such as occur in authentic ME); we drew attention to the reason given in the Trial Identifier itself: “We chose those broad criteria in order to enhance recruitment” and we asked how this can be “evidence-based medicine”?

We expressed concern that these Trials are to include those with fibromyalgia (FM), given that FM is classified by the WHO as a distinct entity (ICD-10:M79), whereas ME is classified at G93.3, and given that FM has a discrete biomedical profile that is entirely distinct from that found in ME/CFS. We provided evidence that the Government already recognises FM to be a quite separate disorder, and we asked how can the deliberate inclusion of patients with FM not result in skewed and meaningless conclusions when the patients being entered into the MRC trials are, from the outset, not clearly defined?

(It is the case that at a meeting of the All Party Parliamentary Group on Fibromyalgia held on 12th May 2004 at the House of Commons, the Parliamentary Under Secretary of State at the Department of Health [Dr Stephen Ladyman MP] announced that GPs would be offered financial incentives and encouraged to identify patients with fibromyalgia and to refer them to the new “CFS/ME” centres, where these fibromyalgia patients would be included in the MRC “CFS” study. It remains to be explained how the lumping together of such a deliberately heterogeneous study population in the MRC trials can yield accurate and meaningful scientific results, when by virtue of the chosen entry criteria, [Oxford 1991] those with authentic ME will have been excluded from the outset [see below], yet despite this, it seems that the results of the MRC PACE trials on “CFS/ME” are likely to be claimed to relate to those with ME).

In relation to NICE, we pointed out that NICE funds the “Effective Healthcare” bulletins which are disseminated throughout the NHS, drawing attention to the issue on CBT and graded exercise as the management of choice for “CFS/ME” (see Effective Healthcare 2002: No.7: Vol 4; 23rd May) and asked how, when the views of NICE have already been established and have been shown to publicly promote the psychiatric model of “CFS/ME”, NICE can be expected to produce unbiased advice in the future without losing face?

2005

Problems and Solution?

Eileen Marshal Margaret Williams 23rd February 2005

This document noted that a Radio interview on 22nd February 2005 with Professor Colin Blakemore (Chief Executive of the MRC) encapsulated the essence of an iatrogenic problem that since 1987 has compounded the suffering of those with ME, and noted that if his pronouncements had been on any other disorder but ME, Blakemore would surely have been pilloried by the media.

Blakemore was asked why the MRC had failed to fund any biomedical research into ME but instead had funded only psychiatric studies that failed to address the neurological, cardiological, immunological and other abnormalities highlighted in international research but ignored in the UK.

His verbatim response was: “I know that this is a very current issue of very great concern to ME sufferers. I think to concentrate on this question of whether ME is thought to be a neurological or a psychological condition actually isn’t going to get us far...I don’t think we should look down our noses at psychological treatments”.

Our paper commented that his declaration that there is no need to worry about whether or not the disorder is either psychological or neurological in causation would seem not to be in accordance with the rigorous approach that is necessary for progress to be made in medical science, and asked if Blakemore really saw no need to search vigorously for the cause of ME: if so, why does such an approach relate only to ME and not to all illnesses whose cause is not yet known, including cancer, multiple sclerosis and lupus? We asked what is the purpose of the MRC if not to conduct research into illness that will provide understanding of (and result in treatment for) that illness?

We noted that Blakemore’s support for the current MRC trials on “CFS/ME” (that have been widely shown to be flawed from the outset by virtue of the entry criteria chosen by the psychiatrists who are running the trials, which *by definition* exclude those with ME) was disturbing, and that Blakemore was wrong to state unequivocally that the current MRC trials include those with ME, as there can be no credible doubt that the Oxford case definition excludes those with neurological disorders: this was confirmed by psychiatrist Anthony David (colleague and co-author with Wessely) who referred to the Oxford criteria shortly after they were published: **“British investigators have put forward an alternative, less strict, operational definition which is essentially chronic fatigue in the absence of neurological signs (but) with psychiatric symptoms as common associated features”** (AS David. Postviral syndrome and psychiatry. British Medical Bulletin: 1991;47:4:966-988).

Given that ME has been classified by the WHO as a **neurological** disorder since **1969**, and given also that the UK Minister of Health (Lord Warner) confirmed on 11th February 2004 in writing that the Department of Health **accepts the correct classification for ME is neurological**, we asked how it can be acceptable for Blakemore to claim that the MRC is funding trials **on ME** when evidence abounds that this is untrue, and how he can assert that the MRC needs “high quality proposals” but then openly support those trials when the inherent design flaws have (to no avail) been repeatedly brought to the attention of the MRC?

(This important issue cannot to be ignored: on 15th May 2004 the MRC trial Principal Investigators, Professors Peter White and Michael Sharpe, posted a notice “Correcting some misunderstandings” on the Co-Cure internet site in which they asserted: “The criteria that we will use to include patients with CFS/ME **do not exclude ME**”: if the Department of Health accepts that the WHO classification for ME is neurological [and the same Department of Health is on record as accepting ME as an **organic** disorder in November **1987** and as reiterating this acceptance on 15th March **1992** when the Under

Secretary of State for Health confirmed in writing that “a physical cause for ME is recognised”, as well as on 16th August **1992**, when the Under Secretary of State for Health stated “ME is established as a medical condition”, and if people with ME exhibit **neurological signs**, and if the Oxford MRC trials entry criteria **expressly exclude those with neurological disorder** and **exclude those with any physical signs**, by what reasoning can those with authentic ME be included in the MRC trials? The ME Association has called for the MRC trials to be abandoned and the MRC has been deluged with letters of concern about these trials, all to no avail. One such letter was from Dr David S, a psychopharmacologist, who wrote to the MRC saying: “I am appalled to have to bring to the attention of the MRC that both massage of the diagnostic criteria and experimental protocol [including the “loss of data” from non-compliers] appears to be taking place in two areas of research into CFS/ME. These are not allegations to be taken lightly and I expect the MRC to launch an immediate investigation”. The question remains: if by definition the MRC trials exclude those with authentic ME, what is to be provided for the 240,000 people that the Government says suffers from CFS/ME, about whom Lord Warner has made the Government’s position quite clear, and who will benefit from the £11.1 million granted to Wessely School psychiatrists?).

Science or Psychology?

Margaret Williams 29th March 2005

While the furore over the MRC trials entry criteria raged on, an equally if not more disturbing concern about these trials was raised again, namely that they might be detrimental and even dangerous for those with authentic ME: whilst Simon Wessely was busy promoting his meta-analysis of the placebo response in CFS as reported on 22nd March 2005 in the Washington Post (“Researchers say people need to be convinced that behavioural therapy and regular exercise can help them overcome symptoms of chronic fatigue syndrome”), scientists were publishing results that showed such regimes **exacerbate** the symptoms in ME/CFS.

This document noted the impressive and significant study by US researchers from the Centres for Disease Control in Atlanta, including world experts such as James F Jones and Suzanne D Vernon (BMC Physiology: 2005:5:5), which was unequivocal: using gene profiling, they found that **“Activities that are physiologic stressors, such as physical exercise, exacerbate the symptoms that define ME/CFS. It is evident that ion transport and ion channel activity segregate cases from controls and that exercise seems to intensify these differences. Several other conditions have been reported that are known to be caused by abnormal ion channels. These conditions include multiple sclerosis and polyneuropathies”**.

As ever, the MRC did not acknowledge this document.

Profits before Patients?

Eileen Marshall Margaret Williams 15th April 2005

Because the MRC trials include compulsory aerobic exercise (even though the deleterious effects of such exercise on those with ME are well documented in the medical literature), we once again drew attention to this, pointing out that it was as long ago as 1988 that there was **“general agreement that (ME’s) distinguishing characteristic is severe muscle fatigability, made worse by exercise. It becomes apparent that any kind of muscle exercise can cause patients to be almost incapacitated (and) the patient is usually confined to bed. What is certain is that it becomes plain that this is an organic illness in which muscle metabolism is severely affected”** (Crit Rev Neurobiol: 1988:4:2:157-178).

We noted that the MRC has resolutely refused to heed submitted concerns about the potential dangers of the PACE trials to those with ME, and that even when sent by Recorded Delivery, these concerns are not acknowledged, let alone addressed.

We again drew attention to the fact that the potential danger is not only because exercise – especially aerobic exercise – is known to cause significant general deterioration and increased pain in those with ME/CFS: it is because those trials involve graded aerobic exercise in patients who may have serious cardiac problems.

Cardiac problems in ME have been documented in the medical literature for over half a century, and our document provided credible references, including evidence that all disabled ME/CFS patients are in heart failure.

We asked if this evidence was deemed to be inconvenient in the UK because it does not accord with Government's preferred policy of off-loading as cheaply as possible the ever-increasing numbers of chronically sick who have no commercial value to the State but who cost it far too much money?

High Standards at the MRC?

Eileen Marshall Margaret Williams 21st April 2005

This document drew attention to a reply sent to Neil Brown by Simon Burden of the MRC, which once again raised the issue of the MRC trial entry criteria.

Firstly, Simon Burden wrote: "When researchers put together a proposal they are required to define the population they are studying": we asked why this does not apply to the CFS/ME trials, pointing out that if those involved with the trials adhere (as required) to the Trial Identifier and select their participants by using the stated criteria (the Oxford criteria), then by definition as set out in the Oxford criteria themselves, those with ME will be excluded from the start, and this is unequivocal.

If there is no such strict adherence to the entry criteria, then the results will be flawed from the outset and therefore meaningless: either the entry criteria are adhered to, or the results will be flawed; there is no other scientifically credible interpretation.

We asked how this accords with the MRC's apparent requirement for "the high scientific standard required for funding"?

The other notable point in Simon Burden's letter stated: "Research proposals in all areas must demonstrate that the research will contribute to maintaining and improving health": we noted that if this is so, then why are exceptions being made in the case of ME patients, and asked how can deliberately putting participants at risk of deterioration by virtue of compulsory graded exercise (however it is administered) be guaranteed not to be harmful, and does such known risk constitute (quote) "maintaining and improving health"?

(It needs to be noted that all trial participants are required to sign a no-liability clause).

We asked the MRC to confirm that, as part of its requirement for "high standards", all participants in the CFS/ME trials will first be screened by means of impedance cardiography to eliminate this very real risk.

We received no reply from the MRC.

Vilified but Vindicated?

Malcolm Hooper Eileen Marshall Margaret Williams 29th April 2005

This 8 page document noted that ME/CFS sufferers have for many years been unjustly subjected to assertions that they suffer not from an organic condition but from either depression or from somatisation disorder, and that such assertions have been promulgated mainly by adherents of the Wessely School.

We drew attention to a 30 page review by Professor Leonard Jason et al from DePaul University, Chicago, that exposed the lack of evidence for such assertions and makes it imperative that the currently advocated management regime propounded by Wessely that is supported by the MRC and funded by Government be held to rigorous scrutiny, since that regime avoids the cardinal issues surrounding ME/CFS and leaves many very sick people with no hope of correct treatment or support.

Significantly, Jason's review extinguishes Wessely's beliefs as unsustainable assumption (but it is those beliefs that are currently driving all UK NHS provision for those with ME/CFS).

We once again noted that the total inadequacy of the psychiatric approach has been repeatedly pointed out to the CMO and to the MRC by us and by others, many of whom emphasised the pressing need for studying sub-groups of “CFS”, and Jason (an undisputed world expert on the disorder) makes the point that such sub-grouping is henceforth essential.

Specifically, Jason stated **“Because the findings of British (psychiatric) studies have been widely disseminated, it is not uncommon for medical practitioners to encourage patients with (ME)CFS to begin an exercise programme and to challenge their beliefs about the medical aetiology of their disorder. CFS represents a heterogeneous syndrome and the lack of consistency in studies might very well be a failure to routinely classify CFS into subtypes. Currently there is a need for investigators to develop subtypes. Most importantly, misdiagnosis may lead to improper treatment and in cases of severe illness, the matter of an incorrect diagnosis can have serious consequences. If there is limited reliability of the diagnostic groups studied because of the failure to attend to subtype differences, the results of any study using such diagnostic categories are likely to be unreliable or invalid”**.

It will be recalled that we had repeatedly brought the need for sub-grouping of the heterogeneous label “CFS” to the attention of the CMO’s Working Group because the various drafts of the report stipulated that sub-grouping was unnecessary and was simply a matter of “semantics” (the view that prevailed in the final report).

In this document we pointed out that, persistently uninfluenced by scientific evidence (and because their unauthorised attempt to reclassify ME as a mental disorder in the WHO Guide to Mental Health in Primary Care was eventually thwarted by members of the UK ME community), Wessely School psychiatrists and their paymasters are currently endeavouring to convince the compilers of the next Diagnostic and Statistical Manual revision (DSM-V, the mental health “bible” that takes precedence over the WHO International Classification of Diseases) to include a new category of “functional somatic syndromes” into which “CFS” would be placed, and “CFS/ME” would thereby become an officially classified mental disorder.

Warning: UK Prime Minister’s Strategy Unit on Mental Health

Eileen Marshall Margaret Williams 26th May 2005

This document drew attention to the Prime Minister’s Strategy Unit’s proposals that people with what are deemed to be “mental” illnesses must “surrender a degree of sovereignty over their mental life”, and that their “notions of autonomy may be fundamentally diminished” (as reported by David Wainwright in an item from “spiked online” entitled “Workers behaving badly”).

We quoted Wainwright: “The UK is mobilising an army of psychotherapists to get people off Incapacity Benefit. The therapeutic apparatus of the British state is poised to undergo a rapid and far-reaching expansion. At a recent meeting of the Prime Minister’s Strategy Unit, the following were proposed: **five thousand extra psychotherapists to be trained in Cognitive Behavioural Therapy; a doubling of the number of psychiatrists, and all new GPs to receive training in psychiatry focusing on treatment of depression and anxiety in the community**”.

We noted that the recent promise of the UK Government to create 7,500 new consultant psychiatric posts is already on record (see European Doctors: Psychiatry in the National Health Service: www.europeandoctors.co.uk).

We noted that it seems that people who were previously accepted by the Government as being physically sick but who are now deemed to be “mentally” sick are not to be tolerated, especially those who are said to suffer from **“the creation of ‘diseases’ like chronic fatigue syndrome for which no evidence of pathology can be found”**.

We drew attention to worrying reports that are already emerging about the new Government centres for “CFS/ME”, notably that if patients withdraw, they will automatically lose their rights to state benefit, and to the fact that CBT is being used to brain-wash patients into accepting that their pain, malaise, gut problems and allergies are simply somatisation and that symptoms will resolve once the correct mode

of thinking is achieved. There is also a worrying obsession with patients' sex lives and there is a refusal to refer people to a pain clinic or to offer any care other than anti-depressants.

(There is evidence in abundance of the impact and effects of this strategy, but attention is drawn to just one example that came to light as a result of an inquiry from an MP on behalf of a constituent with severe ME: in response to a request for a domiciliary visit from the constituent's GP, on 14th October 2003 an NHS consultant immunologist who has been seeing patients with ME/CFS over a considerable area of the UK wrote to the referring GP: "I have seen him a number of times since 1998. He has fairly typical CFS but has maintained beliefs in the condition which I do not think have helped himself (*sic*) recover. The management of this condition is primarily about trying to get and maintain these patients as active as possible. If I do a DV (domiciliary visit) then I am condoning his management of his condition (so) I do not feel a DV is appropriate". Given that this was written by an immunologist who "specialised" in ME/CFS, it would seem to be a classic example of the effects of Wessely School propaganda).

We noted that it is true that "altered medical perception" surrounds and dogs ME (a claim disparagingly made by Wessely School psychiatrists about those doctors who support their ME patients) but that those who display this altered medical perception are in reality Wessely School psychiatrists themselves because they perceive only what they want to perceive by reducing the complex multi-system organic disorder that is ME to mere fatigue, aberrant illness beliefs and a defective personality.

Evidence-based Psychiatry?

Eileen Marshall Margaret Williams 11th June 2005

This document drew attention to the CFS Research Foundation Newsletter 10, November 2004, and to the fact that bona fide research has indicated that in those with ME/CFS there are more gene abnormalities present than are found in cancer sufferers.

We pointed out that there can no longer be any doubt that in ME/CFS there are proven abnormalities in numerous genes, and that such abnormalities are acquired as the result of interactions with the environment as opposed to being hereditary.

Gene expression describes the behaviour of certain genes when attacked by an infection or other insult: some genes become over-active and produce chemicals that cause symptoms seen in ME/CFS, while other genes become under-active or shut down.

The work of US immunologist Roberto Patarca-Monterro illustrates how changes in just one single gene can have wide-ranging consequences: he has identified an abnormal gene in ME/CFS patients that is multi-factorial, affecting the immune response to infection *and* the regulation of calcium and phosphate in bone metabolism *and* the expression of autoimmune disease. His gene studies also reveal consequences within the cardiovascular system, with potential implications for the ability to exercise without biological consequences that are damaging.

We recalled what another world-renowned immunologist who specialises in the disorder, Professor Nancy Klimas from the University of Miami, said in her in-coming AACFS Presidential Address in March 2005: **"Our patients are terribly ill, misunderstood, and suffer at the hands of a poorly informed medical establishment and society"**.

We also recalled a 1992 description of ME/CFS by the Canadian expert Dr Byron Hyde: **"ME/CFS represents a major acquired CNS (central nervous system) dysfunction. This persisting multi-level CNS dysfunction defines the nature of the disease process. The majority of symptoms can only be attributed to a CNS or muscle pathology"**.

Since 1938, there have been thousands of published papers in the medical and scientific literature that document biological abnormalities in ME/CFS, and no-one who is aware of this wealth of information can doubt the reality, the validity and the devastation of this organic multi-system disease.

As Hyde noted, it is the failure of those who are psychiatrically biased to return to the literature that haunts the very basis of their own case definition of “CFS” and their insistence that it is a “mistaken illness belief”.

Questions for the MRC

Eileen Marshall Margaret Williams 18th June 2005

As a result of a letter dated 16th June 2005 from Dr Sarah Perkins (whose title is Programme Manager, MRC Neurosciences and Mental Health Board), this document once again considered the entry criteria for the MRC CFS trials.

Because Dr Perkins had written: “The main entry criteria for the PACE trial are the Oxford criteria. The exclusion criteria of ‘proven organic brain disease’ will be used to exclude neurological conditions of established anatomical pathology such as multiple sclerosis. **It will not be used to exclude patients with a diagnosis of ME**”, we asked the MRC some basic questions:

- Why the MRC is adopting special pleading in relation to ME, when ME is a classified neurological disorder in the World Health Organisation International Classification of Diseases and has been so classified since 1969
- On what scientific evidence is the MRC relying to enable it to disregard this international classification that has been approved by the World Health Assembly
- On what evidence-base is the MRC relying to permit it to disregard recognised research procedure by implementing its own selective modification of the Oxford entry criteria
- Why is it acceptable for the MRC to disregard the substantive body of scientific evidence of neurological compromise in ME in favour of unsubstantiated beliefs of certain psychiatrists
- Given that in 2003 Members of Parliament so excoriatingly criticised the work of the MRC (see House of Commons Science and Technology Select Committee: the Work of the Medical Research Council: Third Report of Session 2002-03, 24th March 2003: HC132), why is the MRC content to continue to support policies and fund projects that are likely to perpetuate such criticism
- In view of the submissions for the funding of biomedical aspects of ME/CFS that the MRC is known to have rejected on the claimed grounds that they were not of sufficiently rigorous quality, what is the explanation for the seemingly more lax standards required for psychiatric research projects such as the CFS trial

The document noted that members of the long-suffering ME community may require their respective Members of Parliament to seek until they obtain believable explanations for such remarkable discrepancies.

Politically Modified Research?

Eileen Marshall Margaret Williams 25th June 2005

This document noted that on 22nd June 2005 Laurie Taylor presented a programme on BBC Radio 4 called “Thinking Allowed”, which Taylor ended with a momentous statement: “The last word must go to the anonymous political insider who recently characterised the present Government’s approach to research in the following manner: **it is not, he said, so much evidence-based policy-making as policy-based evidence-making**”.

That quotation is momentous because it exactly encapsulates the reality: forces are at work that are beyond belief – forces that are intent on “eradicating” both ME and those medical practitioners who support their patients’ belief that it is an organic disorder and who, in the absence of any helpful orthodox interventions, do their best to provide complementary interventions.

The document noted that physicians who genuinely try to help those with ME are themselves victimised, in some cases being reported to the General Medical Council by HealthWatch activists, and it provided a named example.

We noted that after the publication in 1996 of the internationally criticised Joint Royal Colleges' Report on CFS, of which Professor Simon Wessely was known to be the prime mover, the Editor of the Lancet (Dr Richard Horton) courageously spoke out against it, saying on the record: "The college representatives interpreted every piece of evidence pointing to a biological cause in a negative light".

We noted that Horton has won plaudits for his scrutiny of the pharmaceutical industry and that his stance has made enemies, and that more than once Horton has been targeted for his principles, the latest being on 18th June 2005 when he was the subject of a vitriolic attack in The Times from "Establishment" scientists.

Of particular interest to the ME community was that one of the signatories was neuroscientist Dame Nancy Rothwell, the same Professor Rothwell who chaired the MRC Research Advisory Group (RAG) on the direction of future research into "CFS/ME".

We noted that the same edition of The Times carried an item by Tracy Brown that promoted a Discussion Paper extolling the virtues of the peer-review system in the protection of the public. Being aware of the extent of published academic unrest about corruption of the peer-review system, this merited further investigation, which revealed that Tracy Brown is Director of an organisation called Sense about Science, a registered charity whose aim seems to be to "educate" the public so that it unquestioningly accepts industry's agenda for ever-tighter control of the nation's health.

We also noted that apart from Tracy Brown herself, other members of the Sense about Science Working Group that produced the Discussion Paper on peer review included Professor Colin Blakemore, currently Chief Executive of the Medical Research Council, and Fiona Fox, Director of the Science Media Centre (a sibling organisation of Sense about Science), whose Science Advisory Panel includes Professor Simon Wessely.

We noted that the Science Media Centre is funded by pharmaceutical companies and that Fiona Fox has used it to promote the views of industry and to launch fierce attacks against those who question them. Perhaps surprisingly, the Royal College of Physicians (RCP) is a sponsor of the Science Media Centre (although perhaps this is not so surprising when one knows that a past President of the RCP, Professor Sir George Alberti, also sits with Wessely on the Science Media Centre's Advisory Panel).

We further noted the Science Media Centre's links to the online magazine "spiked" whose health writer is (as mentioned above) Dr Mike Fitzpatrick of HealthWatch.

(We subsequently noted that the cost of printing the Discussion Paper from Sense about Science was met by the Medical Research Council, and that Dr Mike Fitzpatrick sits on the Board of Trustees of Sense about Science).

We noted that even though Wessely School psychiatrists had walked out of the CMO's Working Group and did not endorse the final report because it did not categorically affirm "CFS/ME" to be a psychosocial (behavioural) disorder as they believe and assert, it is those very same psychiatrists who are now being awarded massive funding by the MRC to do what they wanted the CMO's report to recommend and who are also calling the shots in the new Government-funded centres for "CFS/ME".

Another Meadow?

Eileen Marshall Margaret Williams 15th July 2005

In this document, we noted that paediatrician Professor Sir Roy Meadow had been struck off the medical register by the UK General Medical Council and that his claims to be a world expert were in ruins, proving that even an acclaimed "expert" is sometimes not to be relied upon and that all such "experts" need to be rigorously questioned about the source of their "evidence".

We quoted what the Chairman of the GMC panel said to Meadow: “Your misguided belief in the truth of your arguments is both disturbing and serious” and, significantly: “You should not have strayed into areas that were not within your remit of expertise”.

We noted that the issue of medical “experts” who are certain they are right is not confined to paediatrics, and we noted parallels in other disputed areas of medicine.

We pointed out that Professor Simon Wessely is certain that ME does not exist except as a false belief and that, like Meadow, he is absolutely certain that he is right and that he, even more than Meadow, compounds his views by repetition *ad infinitum*.

We noted that, like Meadow, Wessely promotes himself as a “world expert” on “CFS/ME” and we asked if it is not time for *his* status as “world expert” to be challenged in the way that Meadow’s status was eventually challenged, because the harm that has flowed from Wessely’s unsubstantiated beliefs seems to be incalculable, with the number of children suffering from severe ME who are being forcibly removed from their homes and being placed in locked psychiatric institutions now amounting to what one NHS consultant paediatrician (Dr Nigel Speight) referred to as an “epidemic”.

We pointed out that for over a decade, questions about possible scientific misconduct and flawed methodology by Wessely in relation to ME/CFS have been raised and published in international medical journals.

We noted that Wessely is a psychiatrist, so it follows that areas of complex medical science such as immunology, vascular medicine and muscle pathology are, to quote again what the Chairman of the GMC Inquiry said to Meadow: “not within your remit of expertise”; this being so, we asked why is it acceptable for Wessely to function outside his remit of expertise, but not Meadow?

We asked how much of the Wessely School theories are based on science and why Wessely has never addressed the massive amount of credible research evidence that shows him to be comprehensively wrong about the nature, cause and management of ME/CFS.

We noted that the GMC regarded Meadow’s unevidenced certainty that he was right as (quote) “fundamentally unacceptable” conduct, and we queried what the GMC might say about Wessely’s equally unevidenced certainty that *he* is right about ME.

ME: Organic or Psychiatric ---Decision Time?

Eileen Marshall Margaret Williams 2nd August 2005

This short document compared two opposing tenets about ME/CFS from the two different camps.

We noted the prime significance of the paper from the stable of Professor Stephen Holgate from the Department of Immunopharmacology at Southampton, where Dr Jonathan Kerr’s team concluded that patients with ME/CFS have reproducible alterations in gene regulation, and that sixteen genes have an expression profile associated with the disorder that can be grouped according to immune, neuronal, mitochondrial and other functions. A neuronal component was identified that is associated with central nervous system hypomyelination and encephalopathy, and the authors stated: “The involvement of genes from several disparate pathways suggests a complex pathogenesis (and) possible molecular bases for the recognised contributions of organophosphate exposure and virus infection, respectively”.

We compared this with the other --simultaneous -- presentation that came from Professor Michael Sharpe (who now holds a Personal Chair in Psychology at the University of Edinburgh and whose inaugural lecture on 12th May 2005 happened to take place on National ME Awareness Day); Sharpe’s lecture was entitled “The Science of the Art of Medicine” and might be summarised as being “How to treat diseases with no pathology”, in which he firmly included “CFS/ME”.

We noted that in publicly releasing his power-point presentation electronically, Sharpe seems to have revealed his real disdain for those suffering from ME/CFS, because submerged within the text is material which seems to encapsulate his belief that “these patients need to change their attitude”, for example:

“It is apparent that the attitude of patients suffering from this chronic state must be changed”.

“The knowledge that experience has shown that certain sensations have resulted from certain activities must be replaced by a conviction that these efforts may be made without harm”.

“Modern medical descriptions of symptoms without pathology: ‘all in the mind’; ‘hysterical’; ‘medically unexplained’; ‘psychosomatic’ ”.

Sharpe seemed to be considering what he called “a psychologically sophisticated NHS”, within which “patients with symptoms that are unexplained by disease” present a problem, and he asked “How big is this problem?” and then answered his own question: “It is a big problem”.

Within his released copy of his power-point presentation, Sharpe also released confidential information about his patients from which they could (and have been) identified, including not only their date of birth and address, but also his own comments, for example: “Putting it on”; “Imagining symptoms”.

We noted that not only does Sharpe apparently dismiss the evidence of serious organic pathology in ME/CFS and consider it to be no more than an “attitude that must be changed”, but he apparently has so little respect for his patients that he failed to take even the most basic care to protect what is clearly confidential information.

(Following media exposure, it has been announced that Sharpe is to face both a University and an NHS inquiry about this significant breach of confidentiality).

A Final Farewell to the Psychiatric Fallacy?

Margaret Williams 13th August 2005

This document highlighted the key points of the latest paper from the Vascular Research Unit at Dundee, findings that could have a significant impact on the safety of the MRC current CFS trials.

It pointed out that this is the first time that raised levels of isoprostanes (highly noxious by-products of abnormal cell membrane metabolism) that precisely correlate with patients’ symptoms have been presented.

As Dr Neil Abbot (Director of Operations at the charity MERGE that funded the research) stated on the MERGE website (www.mererearch.org.uk), the importance of these findings cannot be overstated.

To quote Abbot: “Circulating in the bloodstream are highly reactive molecules, known as free radicals, which can cause damage to the cells of the body, a process called oxidative stress. In healthy people, increases in free radicals are neutralised by antioxidant defences, and it is only when these defences are overwhelmed that cell injury results”.

Of particular significance, as Abbot makes clear, is that **exercising muscle is a prime contender for excessive free radical generation**: “Recent research has demonstrated that **incremental exercise challenge** induces prolonged and accentuated oxidative stress that might well account for post-exercise symptoms in ME/CFS patients.... **many patients currently diagnosed with ME/CFS could have an inflammatory condition** and be in a ‘pro-oxidant’ state”.

The document noted that given so much evidence of serious organic pathology in ME/CFS, perhaps psychiatrist Professor Michael Sharpe needs to re-think his previous pronouncement that “Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service” (*see page 1 above*).

The document suggested that Wessely School psychiatrists now need to understand that it is time for them to re-think their obviously out-dated and potentially damaging approach to those with ME/CFS.

ME: Why No Accountability?

Malcolm Hooper Margaret Williams 18th August 2005

This nine page document was our preliminary submission to the Parliamentary Inquiry; it set out the problem, the facts and the issues surrounding the maze of constructed intrigue in relation to ME/CFS.

It also set out our view that those responsible for this unnecessary intrigue must be held publicly accountable, and it provided a synopsis of some of the issues that we believe a Parliamentary Inquiry needs to understand and address, not least because the human rights of people suffering from ME/CFS are being conspicuously denied without any justification whatsoever.

We posited that it is completely unacceptable that the unsubstantiated personal beliefs of a few immensely influential psychiatrists with indisputable vested interests should continue to indoctrinate UK medicine and the media regarding ME/CFS, and that they should continue to impose inappropriate management regimes upon sick and defenceless patients on pain of having their benefits withdrawn (a situation that has continued unabated for far too long).

Proof Positive?

Evidence of the deliberate creation via social constructionism of “psychosocial” illness by cult indoctrination of State agencies, and the impact of this on social and welfare policy

Eileen Marshall Margaret Williams 30th August 2005

We regard this ten page document as one of the most important of any we have produced.

It noted that the UK ME community has for years urged Government bodies to fund research into the biomedical aspects of ME/CFS, almost always to no avail, to the extent that the ME community realised that there were powerful vested interests at stake that were known to involve psychiatrists of the Wessely School.

Now there is hard evidence of this involvement and it is contained in a book entitled “Biopsychosocial Medicine: An integrated approach to understanding illness” published by Oxford University Press (2005) and edited by psychiatrist Professor Peter White from St Bartholomew’s Hospital, London (Principal Investigator of the MRC CFS trial).

The book arose out of a two-day conference held at the Novartis (pharmaceutical) Foundation in London on 31st October and 1st November 2002, being a joint venture between the Novartis Foundation and a body called One-Health, said to be a not-for-profit company that (quote) “was established in order to promote a system of healthcare based on the biopsychosocial model of ill-health”.

Peter White is Chairman of One-Health; he states that the book was written because “some people believe that medicine is currently travelling up a ‘blind alley’ (and) this ‘blind alley’ is the biomedical approach to healthcare. The biomedical model assumes that ill-health and disability is directly caused by diseases and their pathological processes (but) there is an alternative approach: the biopsychosocial approach is one that incorporates thoughts, feelings, behaviour (and) their social context”.

Twenty-eight “international experts in the field” were invited, many of whom are already known to the ME/CFS community: apart from Professor Simon Wessely (who chaired the entire conference), others who have featured in the fate of those with ME included Professor Michael Sharpe, Professor Trudie Chalder (a former Registered Mental Nurse who works with Wessely and is now one of the Principal Investigators of the MRC CFS trials), Dr Mike Fitzpatrick (referred to above) and Professor Mansel Aylward (then at the Department of Work and Pensions but recently appointed Chair in Psychosocial and Disability Research at Cardiff, where he is also Director of the UNUMProvident Centre for Psychosocial and Disability Research).

Our document quoted extensively from the book and it is strongly recommended that members of the Parliamentary Inquiry read “Proof Positive?” for themselves, because it summarises what by any standards is a most disturbing scenario relating to the health of the British nation, notably the intended replacement of biomedical science by the wholesale adoption of psycho-social dogma.

Some illustrations include:

Simon Wessely: "I seem to have spent much of the last decade sitting on grant-giving bodies. Cognitive behaviour therapy has transformed the management of many chronic symptomatic conditions. That psychological and social factors contribute to disease is clear (but) not even Government would dream of tackling these issues without anchoring policy".

In response to the question "What are the barriers to healthcare systems using a biopsychosocial approach and how might they be overcome?", Professor Kate Lorig from Stanford, USA, provided some telling answers: when asked by Professor Mansel Aylward how did she recruit people into the biopsychosocial model, she replied: "I'd put real marketing experts onto it. Are (people) tired? If so, come along. We (recruit participants) in churches and community halls. This past Easter I went to mass twice, and I'm Jewish. Between myself and the staff we covered 17 masses. We just take their names and addresses and then call them later. The system has to go to them, you don't ask them to go to the system".

Mike Fitzpatrick: "It is interesting to contrast the approach Kate Lorig is talking about with what we are familiar with about patient campaigns, which often have a very activist feel to them, such as the ME campaign".

Kate Lorig replied: "The two master trainers in the UK both came from patients groups. We have had virtually no resistance from patient groups".

(This would seem to accord with Sharpe's report for UNUM Provident's "Trends in Health and Disability" 2002, in which he stated: "There are glimmers of progress. One of the major patient charities, Action for ME, is aligning itself with a more evidence-based approach").

Trudie Chalder (to Kate Lorig): "It is clear that you are a very effective cognitive behavioural psychotherapist and I want to congratulate you on your programme. It sounds marvellous".

Kate Lorig: "We have to develop key messages, which the healthcare system gives consistently".

Simon Wessely: "We accept that. This is what we do in treatment programmes. But we also know that even getting patients to see us is a challenge because of their fear-avoidance beliefs".

Peter White: "The biopsychosocial approach is important in addressing disability associated with all chronic ill-health (including) common disorders such as chronic fatigue syndrome. Healthcare systems will routinely incorporate the biopsychosocial approach when convinced of its economic advantages. Teaching the skills necessary for professionals to feel confident (in the biopsychosocial approach) is more important than persuading them to ask the appropriate questions. Because many patients now use the internet for information on their health, we should make greater use of this medium to get the right message across".

Trudie Chalder: "We could make a start with youngsters in schools. My experience is that they are much easier to educate. The only barrier is the parents. Once we have the child on our side, we are in a very good position".

Simon Wessely: "Mansel Aylward, you are involved with policy definitions. What have you heard here that might influence your Secretary of State?"

Mansel Aylward: "I have been given a lot of information that reinforces some of the messages that I have passed on to decision makers. We had some great difficulty last year persuading certain people that the way forward lay with a biopsychosocial approach. It is very difficult to get the Department of Health, amongst others in Government, to favour interventions adopting the biopsychosocial approach, but in recent months I'm beginning to see a change".

Simon Wessely: "What made some of the policy makers change their views?"

Mansel Aylward: "Systematic reviews of the literature (*note that these are either performed by or are mostly relying on published papers by Wessely School psychiatrists*) to support the biopsychosocial

concept. Recent meetings of focus groups of key opinion makers (now) support – with authoritative and expert opinion – the value of biopsychosocial approaches. There are going to be some developments soon”.

Our document noted that Aylward used the term “expert opinion” and not expert “**evidence**”.

Greville Mitchell (Patron of One-Health company): “If you go to Gordon Brown (Chancellor of the Exchequer) and say, ‘We can prove to you that if we address this issue, we can save £2 billion’, then you have his full attention”.

Mansel Aylward: “That is the approach that has been taken”.

Brian Marien (from the Health Psychology Unit, King Edward VII Hospital, Midhurst, West Sussex): “I like (the) idea of changing patients’ (beliefs), because I don’t think we are going to change the professions”.

Mike Fitzpatrick: “The line from the ME Association is that if you, as a GP, say you are sceptical about the ME label, the Chief Medical Officer has stipulated how this must be dealt with. This reflects endorsement at the highest level of policy of a disease label that is not supported by the evidence – it is a completely irrational formulation”.

Mansel Aylward: “It doesn’t follow that all of that report is supported by everyone in Government service. The Department of Work and Pensions doesn’t necessarily endorse all that is in the Working Party’s report to the Chief Medical Officer. I am also mindful of the views of those who, as members of that group, distanced themselves from some aspects of the report”.

Mike Fitzpatrick: “Nonetheless, this was the line and it is very much promulgated that GPs should follow this. It is a consensus forged by excluding many of the people in this room who have been involved in this area. This illustrates a big problem: the Government are linking up with patient activist groups to dictate an approach which is not actually going to be beneficial to patients”.

Greville Mitchell: “The question in the title of this meeting was whether the biopsychosocial model is a necessity or a luxury. To me, the answer from this meeting is that it is clearly a necessity. It has been a brilliant meeting”.

Our document noted that it may have been a “brilliant” meeting as far as most of the participants were concerned, but it left unanswered a glaring question: one of the participants (Professor Robert Lewin from the Department of Health Sciences at York) said “As we all know, cognitive behavioural therapy gains tend to fade over time”; this being known to be so, we asked how the psychosocial model that depends on CBT can be sold as being attractive to the Chancellor of the Exchequer? Is the Chancellor being deceived? If CBT has no lasting benefit, how can it be cost-effective?

Our document noted that, illuminating as these extracts are, it was the final discussion that struck the most chilling resonance because it seemed to embody the deliberate social construction of their own version of reality by these influential and determined social constructivists: we noted that this is alarming because there are parallels in comparatively recent history that are forgotten at humanity’s peril.

It is disturbing that in twenty-first century medicine in the UK, members of the One-Health company seem intent on rejecting the hard-gained, evidence-based biomedical model of disease and substituting their own unproven and retrograde biopsychosocial model that is designed to change people’s beliefs (which they themselves expediently refer to as “evidence-based”).

Overall, the meeting seems to have crystallised One-Health company members’ clear intention to exert an unchallenged stranglehold over people suffering from what One-Health company members deem to be “medically unexplained symptoms”, in that the best interests of such sufferers are seemingly to be sacrificed on the pecuniary altar of the State by means of a psychiatric regime with which the propounders themselves just happen to be financially involved.

It certainly leaves those who suffer from the savage disease ME/CFS without even a modicum of hope.

More Proof Positive?

Eileen Marshall Margaret Williams 4th September 2005

In this document we noted the astonishing response to “Proof Positive?” and that there is clearly a groundswell of deep unrest within the UK ME community that indicates the powerful strength of feeling against the repeated failure of Government policy-makers to heed the significant amount of international scientific evidence of organic pathology that has already been demonstrated, and instead to rely on the unproven beliefs of the proponents of the biopsychosocial model of the disorder who, on their own admission, are targeting and indoctrinating these Government policy-makers.

From the numerous responses we received, one in particular stood out: it pointed out that the biopsychosocial model of ME/CFS regards the disorder as a comprehensively somatisation (psychiatric) disorder, and asked how this sits with the fact that it was these same psychiatrists themselves (Simon Wessely and Peter White) who in the 1996 Joint Royal Colleges’ report stated that:

- (i) **25-40% of ME/CFS patients do not fulfil the criteria for psychological disorders** (chapter 4 / Summary)
- (ii) **nearly all studies find that between one-quarter to one-third of those who fulfil the criteria for CFS do not fulfil any criteria for psychiatric disorder and that** (*quote*) **“any simple equation of CFS with psychiatric disorder is thus erroneous”** (chapter 7:7.6)

We asked where is the published research evidence since 1996 that enables the same psychiatrists now to claim that apparently 100% of ME/CFS patients suffer from a psychiatric disorder that must be “treated” by coercing them into changing their (correct) belief that they have a serious organic disorder?

Conclusion

In a central page spread in the current issue of the Times Educational Supplement (5th November 2005) David Newnham provides an in-depth article on ME/CFS, pointing out that of the estimated 240,000 sufferers in the UK, an increasing number are children, some as young as five; he points out that 80% of affected children will fall behind with their studies and may drop out of education altogether; he also points out that only a small percentage of sufferers return to normal health and that many sufferers never recover.

Newnham quotes two parents: one mother said her daughter became “bedbound, cannot swallow, cannot open her hands, cannot move her feet apart, cannot turn in bed, cannot turn her head, doubly incontinent – totally dependent”; another girl had been very active but on becoming ill “went through a stage where she felt really dizzy, as though on a boat...the rooms used to go totally black”; the girl’s speech became slurred and she felt so sick that she was barely able to eat.

In a paper just published (Am J Occ Ther: 2005:59:497-506), the author is blunt: “The social model of disability has had a major influence on contemporary understandings of the causes of disability. The purpose of this study was to examine the adequacy of the social model for explaining the disability experience of persons with chronic fatigue syndrome”. It concluded that it is important to recognise that the social model of ME/CFS as promoted by currently dominant concepts may not capture the full reality.

On 7th October 2004 Professor Charles Lapp was the contact person for a press release of the AACFS; the press release was unequivocal: CDC researcher Dr William Reeves, Chief of the ME/CFS research programme, reported that **ME/CFS patients are more sick and have greater disability than patients with chronic obstructive lung disease or cardiac disease, and researchers found that the strongest predictor of the development of ME/CFS is the severity of the acute illness at onset, and that psychological factors played no role.**

We suggest that Inquiry members look at our document entitled **“Quotable Quotes about ME/CFS”**

of 17th July 2004 (available online at www.meactionuk.org.uk), just some of which are provided here (all are from experienced medical professionals and all are fully referenced):

1956: “In nearly every patient there are signs of disease of the central nervous system”

1989: “Many of the immunological and physical features cannot be explained by mental illness”

1989: “The disabling weakness and exhaustion a patient with ME/CFS experiences is so profound that “fatigue” is probably an insult”

1990: “The results suggest that ME/CFS is a form of acquired immunodeficiency”

1991: “The most compelling finding was that the NK (natural killer) cell cytotoxicity in ME/CFS was as low as we have ever seen in any disease. This is very significant data; ME/CFS patients represent the lowest cytotoxicity of all populations (including HIV AIDS) we have ever studied”

1992: “Patients with ME/CFS may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system”

1992: “ME/CFS has an organic basis; it is not a psychiatric illness” (CDC Surveillance Study)

1993: “The worst cases have both an MS-like and an AIDS-like clinical appearance. The most difficult thing to treat is the severe pain. Most have abnormal neurological examination. 80% of cases are unable to work or attend school. We admit regularly to hospital with an inability to care for self” (Testimony before US FDA Scientific Advisory Committee)

1995: “In my experience, ME/CFS is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages”

1999: “The most important thing is not to have (patients) do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA”

2001: “In ME, there are chronic sequelae which may affect the myocardium”

2001: “ME/CFS is as disabling as lupus, multiple sclerosis and rheumatoid arthritis. Three quarters of medical professionals responding to the survey believe that it is as or more disabling than other chronic diseases”

2004: “There is no word in the English lexicon that describes the lack of stamina, the paucity of energy (and) the absolute malaise that accompanies this illness”.

Despite all that is known about the disorder there is no provision of care throughout the NHS for patients with authentic ME/CFS: many have been abandoned, denigrated and dismissed; benefits have been withdrawn and patients left without the essential support and care they need.

What is so appalling is that this is not ignorance, but the deliberate and determined suppression by Wessely School psychiatrists of the available medical and scientific evidence that has demonstrated organic pathology in a very serious and complex disorder.

As Dr V Rippere wrote in the Journal of the Royal Society of Medicine (1992:85:59): “It is worrying that many neurological patients may be relegated to the disadvantaged status of ascribed mental illness because of systematic abuse of the doctor’s diagnostic authority”.

It is time that a Parliamentary Inquiry held to account those responsible for this systematic abuse.