

**COMMENTS ON THE CMO'S DRAFT REPORT ON CFS/ME**  
**(19 June 2001 version) SUBMITTED BY THE 25% ME GROUP FOR**  
**THE SEVERELY AFFECTED**

29<sup>th</sup> June 2001

On behalf of advisers and colleagues, the Co-ordinator of the 25% ME Group for the Severely Affected wishes to record his gratitude to the editors of this latest draft Report for the considerable improvements which have been incorporated in this version and he wishes it to be noted that he and his advisers are encouraged to see that the plight of the severely affected has been widely acknowledged throughout the draft Report. It is to be hoped that these substantial and welcome improvements which more accurately portray the reality will not be edited out of the final Report under determined pressure from those who are known to hold strongly opposing views.

Whilst wishing to record appreciation of the considerable effort which has clearly been taken by the editors, there remain areas of concern over certain key aspects of the draft Report, which we elucidate in this document. It is vital that these are addressed and corrected in accordance with the published scientific evidence before we are asked to endorse the final Report because in our view (and in the view of the other patients' organisations) these areas are central to the prevailing misunderstandings and controversy highlighted within the draft Report and they underlie the current difficulties which the draft Report has acknowledged.

**Concerns about the use throughout the draft Report of the term CFS/ME**

**[Few references are listed in this document, as 92 pages of relevant references have already been sent to the CMO's Working Group and will therefore be available to the editors]**

We start by re-visiting our long-standing concern over the use of the combined term "CFS/ME", given that the term "CFS" means different things to different people.

It is acknowledged that the term "Syndrome, Fatigue, Chronic" is listed in the Code Index of the current version of the International Classification of Diseases and that in the tabular index this code (ICD 10 G.93.3) refers to ME and postviral fatigue syndrome. It is, however, the case that the tabular list does not list every term which is included in the alphabetical Code Index. Our concern arises from the fact that currently in the UK there are two differing interpretations of the term "CFS" in common use, one being psychiatric and the other being organic.

On the one hand, there is an extensive published record of papers by psychiatrists of the Wessely School promoting their view that CFS/ME is a psychiatric condition. On the other hand, CFS/ME is formally classified as a neurological disorder in ICD 10.

Wessely's views about CFS / ME (and he is named as the author of those views) have already been incorporated into the WHO Guide to Mental Health in Primary Care (2000) at sections 6.2 and 6.3, which state "*Chronic Fatigue Syndrome...is often known as 'ME'. What makes people develop chronic fatigue syndrome? The pressures of life... depressed mood... lifestyle... personality style. What can keep fatigue going? Avoiding activity. Various methods of rehabilitation have been shown to be helpful. These include cognitive behavioural therapy and ...graded programmes of exercise. Negative thoughts are common in Chronic Fatigue Syndrome*". Given that this appears in a Guide to Mental Health based on Wessely's own belief about the nature of CFS, it is unsurprising that there is no mention of the physical signs and serious symptoms invariably found in Ramsay-defined ME or in strictly defined ( ie. non-Oxford /Wessely et al) core CFS .

Fred Friedberg, Clinical Professor in the Department of Psychiatry at the State University of New York makes this distinction succinctly: "*descriptive studies of CFS patients in England, the US and Australia suggest that the CFS population studied in England shows substantial similarities to depression, somatization or phobic patients, while the US and Australian research samples have been clearly distinguished from depression patients and more closely resemble fatiguing neurological illnesses*" [ref: *A Subgroup Analysis of Cognitive Behavioural Treatment Studies. Fred Friedberg.JCFS 1999;5:3-4:149-159*].

How, then, can the CMO's Working Group equate the two terms ME and CFS without making it clear that CFS as used by psychiatrists of the Wessely School does not represent the same patient population as the more strictly defined or "core" CFS which in ICD 10 G.93.3 is equated with ME? In our opinion, this constitutes the root of the problem which the CMO's Report is mandated to address.

With this in mind, advisers to the 25% ME Group have been in direct communication with the WHO in Geneva and it has been confirmed by the editor of the International Classification of Diseases that **there are no plans whatsoever to remove ME from its formal classification as a neurological disorder and to re-classify it in the psychiatric section in the next ICD (Version 10.2) which is due in 2003.**

We are informed by the WHO that when considering the correct classification of ME/core CFS, the syndrome should be regarded as neurological and not as psychiatric, and that the fatigue states which are currently classified in ICD 10 at section F48 as "Behavioural and Mental Disorders" do not refer to ME/CFS. Specifically, we are advised that the "Fatigue" classified at section F 48.0 (including neurasthenia) **is not the same disorder as ME / CFS**, a claim which has frequently been made by psychiatrists and supporters of the Wessely School. We are grateful for this clarification from the ICD.

Obviously we accept that disease labels change as medical knowledge increases (for example, AIDS used to be called GRID, which stood for Gay-Related Immune Disorder) but we cannot accept a change of classification which is not supported by the WHO.

Moreover, we are informed by the editor of ICD that it is unacceptable for there to be two differing categorisations of CFS/ME under the WHO banner (one in a mental section and one in a neurological section) and that this is something which will be looked into. We are informed that for legal purposes, the ICD takes precedence. This is because the classification it contains has been approved by the World Health Assembly, whereas the Guide to Mental Health in Primary Care has not been approved by the World Health Assembly.

We therefore ask that the editors of the final Report of the CMO's Working Group will take care to clarify the correct situation, which is that CFS/ME is **not a psychiatric condition but a disorder of the nervous system as classified by the WHO in ICD 10.**

**It is necessary to recall that ME was classified as a disease of the nervous system in ICD 8 (which was approved in 1965 and published in 1969), and that it is listed both in the tabular list and in the Code Index as Code 323 (page 173).**

**ME continued to be classified as a disease of the nervous system in ICD 9 (approved in 1975 and published in 1979), both in the tabular list and in the Code Index, where it is coded as 323.9 (page 182).**

**Page 4: Chapter 1. Introduction** In the very first paragraph a major cause of conflict arises because the draft Report states *“Thus the report is structured so that the main part, available in print form, considers the ‘common ground’ that should be emphasised, while additional detail and some varying views are presented in online annexes”*.

We strongly disagree that the CMO's Report should be produced in two separate divisions which will not entirely concur with each other. In our view, it is imperative that everyone has equal and universal access to the complete Report and that the main (printed format) part of the Report is not perceived as an attempt to placate patients whilst the online annexes are perceived as the version which medical professionals would be encouraged to prefer and use. A “them and us” dimension would merely perpetuate the very situation which this Report is attempting to eradicate. It would certainly be likely to generate yet more distrust and suspicion. To have two distinct parts to the Report would leave the door wide open for continuing mismanagement of patients by just one group of influential doctors and their therapists who refuse to accept the ever-growing number of biomarkers which support an organic pathoaetiology, particularly bearing in mind their much-published and entrenched view that ME does not exist, that “CFS” is wholly amenable to psychotherapy and that PRISMA's version of cognitive behavioural therapy offers the best way of treating and managing patients. In this respect we are mindful that Lord Falconer of Thoroton, as Minister of State in the Cabinet Office, has confirmed in a written parliamentary reply that *“where relevant to the UK's e-government initiative, (PRISMA's) results will be taken into consideration”*. We are thus concerned that online annexes may serve to encourage the continued promotion of inappropriate and damaging interventions in ME/core CFS.

**Page 6: paragraph 1.4** “*Experts outside of these groups were consulted as part of the wider clinical network*”. In the interests of open and transparent policy, who are these experts and will they be named in an appendix? In which discipline is their expertise? In order to refute any suggestion of bias as occurred in the 1996 Joint Royal Colleges’ Report CR 54, it is necessary that the names of these experts are public knowledge.

**Page 11: paragraph 1.5.3.1** “*Other factors which appear to be associated with poor prognosis include the coexistence of psychiatric...illnesses*”. This implies that psychiatric comorbidity is universal in CFS/ME but unbiased evidence does not support such a view. Psychiatric comorbidity may well be prevalent in patients who meet the 1991 Oxford definition of CFS (the case definition of which specifically includes patients with psychiatric illness) and / or the 1994 CDC case definition (which specifically excludes patients who have any physical signs on examination, thereby positively excluding those with Ramsay-defined ME) but it is certainly not the case as far as ME/core CFS is concerned. A supposition such as this is unscientific and misleading. Many non-biased studies have found that there is no higher incidence of psychiatric comorbidity than in controls [*for example Neuropsychological Function in Patients With Chronic Fatigue Syndrome, Multiple Sclerosis and Depression. Ella Daly, Anthony L Komaroff et al*

*Applied Neuropsychology 2001:8 (1):12-22. This important paper concludes “Our findings support the view that the cognitive deficits found in CFS patients cannot be attributed solely to the presence of depressive symptomatology in the patients. **They are consistent with reports of brain alterations in CFS patients** (eg Lange et al, 1999)”].*

**Page 11: paragraph 1.5.3.1** “*Factors apparently unrelated to prognosis include...immunological profiles*”. We would point out that such a supposition is in stark contradiction to the published evidence: credible research published in reputable journals demonstrates that changes in different immunological parameters correlate with particular aspects of disease symptomatology and with measures of disease severity ie. studies show that there is a specific correlation between the patient’s immunological profile and severity of symptoms (and hence prognosis). [There are many studies which show this, for example: *A study of the immunology of the Chronic Fatigue Syndrome: Correlation of immunologic parameters to health dysfunction. IS Hassan, W Weir et al Clin Immunol Immunopathol 1998:87:60-67*]

**Page 28: Chapter 3: Key Messages box** “*most abnormalities seem to be consequences of the disease rather than primary processes*”. Apart from some of the psychiatric literature, reputable published evidence is unequivocal that the direction of causality remains unproven. Specifically, the non-psychiatric literature is clear that the observed abnormalities in ME/core CFS are not simply the consequences of reduced activity or mood disorder.

**Page 28: Chapter 3: Key Messages box** “*Current evidence does not allow.... useful delineation of subgroups*”. There is overwhelming published evidence of different findings in differing subgroups [*for illustrations of the evidence, see the 18 references in*

*the section Where is the evidence that there is a careful need for sub-grouping within “CFS”? on pp 9 - 11 of the document dated 9<sup>th</sup> March 2001 entitled Matters of continuing concern submitted by the 25% ME Group for the Severely Affected already submitted to the CMO’s Working Group].*

**Page 34: paragraph 3.2.4 Maintaining Factors** “ *Mood disorders - Disorders of mood...occur in a large minority of CFS/ME sufferers*”. We would point out that “ *a large minority*” is a contradiction in terms. More importantly, this assertion is not supported by the international published evidence. Disorders of mood may undoubtedly maintain illness in some psychiatric subgroups of Oxford-defined CFS, but there is absolutely no evidence that disorders of mood occur in Ramsay-defined ME.

**Page 34: paragraph 3.2.4 Maintaining factors** “*Illness Beliefs - certain beliefs about the cause of the illness have been linked with prolonged CFS/ME*” Whilst this paragraph does go on to state “*These beliefs could be partially correct*”, it also states that “beliefs” could act as obstacles to recovery. Again, this could well be true in psychiatric subgroups of CFS but it is certainly incorrect in Ramsay-defined ME and there is not a shred of evidence which supports this incorrect claim. That is why we are so concerned about the Working Group’s determination to combine the two together as one unified disorder without making it very clear that there are two polarised views about the nature of “CFS”.

**Page 35: paragraph 3.2.5 Possible pathophysiological mechanisms** “*Immunological abnormalities.... their relationship to the illness has not been established*”. This is totally incorrect. See our comments above on paragraph 1.5.3.1 We also draw particular attention to an excellent overview of the immunological aspects of ME/core CFS which demonstrates that immunological abnormalities **are** a feature of ME/core CFS [ref: *Review: Immunology of Chronic Fatigue Syndrome. Roberto Patarca, Timothy Mark, Mary Ann Fletcher, Nancy Klimas. JCFS 2000:6: (3/4):69-107*].

**Page 35: paragraph 3.2.5 Possible pathophysiological mechanisms** “*Autonomic abnormalities are mostly closely associated with inactivity*”. This is untrue for ME/core CFS (ie. non-Oxford defined CFS), and we suggest a more careful appraisal of the literature which shows it to be untrue. We mention just one reference here which refutes this unsubstantiated assertion [ref: *Neuroendocrine Correlates of Chronic Fatigue Syndrome:A Brief Review. Mark Demitrack. J psychiat Res 1997:31:1:69-82*] Moreover, at the American Association for Chronic Fatigue Syndromes (AACFS) Fifth International Research and Clinical Conference held in Seattle in January 2001, Professor Anthony Komaroff said that there is “substantial evidence” that both the sympathetic and parasympathetic nervous systems are abnormal in ME/core CFS; a wealth of studies (about 85%) confirm autonomic nervous system dysfunction in up to 90% of ME/core CFS patients (none found a “close association” with inactivity, rather they found that autonomic nervous system dysfunction is integral to ME/core CFS pathology). For interest and comparison, we here mention findings by French neurologists from Hospital R.Salengro, Lille, France who aver that the frequency of autonomic dysfunction in

multiple sclerosis has been underestimated (ME/core CFS has been known as atypical MS and is known to share many features according to neurologists such as Charles Poser of Harvard and to Abhijit Chaudhuri of Glasgow who confirmed this in his presentation to MSPs on 4<sup>th</sup> April 2001 --- see below) These French neurologists show that multiple sclerosis patients have autonomic dysfunction and that it is related to spinal cord atrophy, **not** to deconditioning [ref: *Autonomic dysfunction in multiple sclerosis: cervical cord atrophy correlates* DG Review by Veronica Rose. *Journal of Neurology* 2001:248:4: 297-303]

**Page 36: paragraph 3.2.5 Possible pathophysiological mechanisms**

***“Biopsychosocial model - (this model) suggests that, once an illness has started, its expression is affected by beliefs, coping styles and behaviours”*** In ME/core CFS, such a proposed model is no longer credible in the light of all the biomarkers of organic pathoaetiology which are now well-documented. Even a cursory consideration of the signs and symptoms found in the severely affected ME/core CFS sufferer (as distinct from the psychiatric subgroup of Oxford-defined CFS) shows such a model to be a nonsense. Signs such as Rombergism, nystagmus and neuromuscular incoordination, symptoms of vasculitis, pancreatic, adrenal and thyroid dysfunction including low free T3, an enlarged liver with disruption of liver enzymes, convincing laboratory evidence of an abnormality in cholinergic activity within the vascular endothelium with disruption of microvascular integrity, laboratory evidence of delayed recovery of muscle after fatiguing exercise, plus evidence of brain stem impairment **cannot possibly be the consequence of beliefs**, any more than can measurable orthostatic hypotension, hair loss, mouth ulcers, an increased CD4 / CD8 ratio, inverted T waves on Holter monitoring and reduced lung function tests, all of which are clearly documented in the non-psychiatric ME/core CFS literature.

**Page 36: Definitions and terminology: paragraph 3.3.1** *“Encephalomyelitis” ...is*

*incorrect because the term implies a pathophysiological process for which no evidence exists”*. Evidence for central nervous system inflammation does exist and that evidence has already been provided for the CMO’s Working Group (see our Submission to the WG dated 9<sup>th</sup> March 2001 entitled *Matters of Continuing Concern*, page 5]. An Editorial in the Lancet stated about ME *“In nearly every patient there are signs of disease of the central nervous system”* [ref: *A New Clinical Entity? Editorial:Lancet* 26 May 1956].

In addition to actual evidence, there is much to suggest an inflammatory process [ for example: *A Chronic Illness Characterized by Fatigue, Neurologic and Immunologic Disorders, and Active Human Herpesvirus Type 6 Infection* Dedra Buchwald, Robert C Gallo, Anthony L Komaroff et al. *Ann Int Med* 1992:116:2:103-113: *this paper states “Neurologic symptoms, MRI findings and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system”*]. We agree with Dr Betty Dowsett, former President of the UK ME Association (whose personal experience of UK ME patients is second only to that of Dr John Richardson) when she states *“...the use of brain imaging scans clearly indicates that metabolic dysfunction in the brain stem and the spinal nerve radiations which traverse it is initially associated with viral*

*(inflammatory) damage and are the major cause of the cardinal symptoms of ME*". She also makes the point that the 1988 definition of "CFS" and its 1994 CDC revision elevated tonsillitis, glandular enlargement and fatigue to unreal importance, whilst overlooking the characteristic encephalitic features of the genuine illness. [ref: *A Rose by Any Other Name. Dr B Dowsett. The Quarterly, (Newsletter of the 25% ME Group for the Severely Affected) Summer 2001*]. Central fatigue, stress-induced weakness, autonomic nervous system dysfunction and the breakdown of homeostasis of hormonal and other vital functions are indeed features of ME/core CFS [ref: *Polioencephalitis and the Brain fatigue Generator Model of Postviral fatigue Syndromes. Bruno RL et al JCF 1996: 2:(2/3):5-27*]. We once again point out that those suffering from ICD classified ME (a neurological disorder) **are permanently excluded from being blood donors, whereas those with psychiatric disorders are not permanently excluded from being blood donors** [ref: *Guidelines for the Blood Transfusion Services in the United Kingdom 1989, 5.410*].

**Page 48: paragraph 4.1.2** *"Most people with CFS/ME can expect to improve"*.

To state that "most" people with CFS/ME improve is incorrect. Statistics clearly show that "most" people with ME/core CFS do not improve significantly. The evidence (all in the public domain) shows that at best, one third regain up to 80% of their premorbid levels (ie. never 100% of premorbid levels); another third experiences remissions and relapses, with each relapse leaving them more incapacitated, whilst the remaining third continues steadily to deteriorate into severe incapacity and dependency. It is this latter section with whom the 25% ME Group for the Severely Affected has most experience.

Dr Abhijit Chaudhuri, Senior Clinical Lecturer in Neurology at the University of Glasgow, where thousands of ME/core CFS patients have been seen, is on record as stating that **80% of patients do not get better**. At his presentation on 4<sup>th</sup> April 2001 to the Cross Party Group on ME in the Scottish Parliament, Dr Chaudhuri informed MSPs that **there is a low rate of spontaneous recovery** (and for the record, he also said that the condition is not due to depression, hysteria or somatisation **in correctly diagnosed cases**). Additionally, in their leaflet entitled "ME/CFS/PVFS", the ME Association makes it plain on page 13 that the percentage of patients who return to normal health is "fairly small".

**Page 51: paragraph 4.2.1.1** *"Where....CFS/ME is one of the possible diagnoses, a limited set of investigations is usually appropriate"*. On this important issue, we refer the editors to our last submission to the WG. To state that only a limited set of investigations is necessary is inappropriate advice and it is in complete contradiction to informed medical opinion. World-class expert opinion is that basic laboratory testing is insufficient for these patients, who require advanced and detailed investigation. Clinicians of experience and expertise frequently make it known (in the literature as well as anecdotally) that basic screening tests are inadequate for this complex disorder.

**Page 55: paragraph 4.2.2 Physical examination** *"Findings are frequently normal in CFS/ME"*. This is not the case in ME/core CFS, where findings are physical and visible albeit it discrete and could be overlooked by an ill-informed, careless, disinterested or

antagonistic physician. A list of the more common physical findings has already been provided for the WG in our submission dated 9<sup>th</sup> March 2001 entitled Matters of continuing concern. Those physical findings include nystagmus, sluggish visual accommodation, abnormality of vestibular function with positive Romberg test, abnormal tandem or augmented tandem stance, abnormal gait, cogwheel movement of legs on testing, hand tremor, fasciculation, hyper reflexia without clonus, facial vasculoid rash, vascular demarcation which can cross dermatomes, evidence of Raynaud's syndrome, mouth ulcers, hair loss, a labile blood pressure, flattened or inverted T waves on Holter monitoring, orthostatic tachycardia, shortness of breath, abnormal glucose tolerance curves, enlarged liver and destruction of fingerprints due to perilymphocytic vasculitis. We agree, however, that such signs are not found in all sub-groups of CFS/ME; this is why, in the interests of good science (and in accordance with world expert opinion --- see our previous submission to the WG in which the need for studying subgroups is fully referenced) we urge careful study of the various sub-groups.

**Page 55: paragraph 4.2.2.1 Specialised tests** *“tests that are currently used in research, for example for specific immune markers or neuroimaging should not be part of clinical evaluation”*. We strongly disagree with this statement; we believe it is essential that people in whom a genuine diagnosis of ME/core CFS is considered probable ***must*** undergo such investigations. In our view, not to investigate such patients fully would be negligent and could be open to indefensible litigation on the grounds of failure to pursue investigation of possible causes and of not monitoring a condition adequately. This is true especially if it could be shown that a more pro-active approach may have brought relief earlier ie. if results of such tests confirmed that certain therapies are contra-indicated. Comprehensive investigation might also prevent an incorrect diagnosis of psychiatric illness from being in the patient's medical records. Such a diagnosis, even if later proved to be incorrect, is impossible to remove from the records and leads to a lifetime of damaging and unjustified (but entirely preventable) prejudice from many quarters, including the Benefits Agency and certain Insurance companies who refuse to pay benefit if the policy holder is deemed to have a psychiatric condition.

**Page 57: paragraph 4.2.3.1 Self management** *“An example of a self-management course for people living with long-term illnesses: the course involves.... six weekly sessions each of about 2 ½ hours that aim to improve people's health by giving them the skills....to take more control of their lives.... to make best use of professional advice and to..... help others as well as themselves”*. This is nothing short of insulting to the majority of patients with ME/core CFS; further, it does not accord with the Report's acknowledgment that the severely affected cannot look after themselves at even the most basic survival level and often cannot leave their bed / home.

**Page 62: paragraph 4.3.2.1 Cognitive behavioural therapy** *“CBT combines activity management....goal setting and a psychological approach to address unhelpful thoughts and beliefs about CFS/ME. **Graded -exercise therapy** “There is good evidence that supervised and graded exercise therapy improves outcome in some patients. The place of this therapy for severely affected patients is currently uncertain”*. We contrast this with



the advice of Dr Melvin Ramsay (the UK's greatest expert on ME until his death in 1990) who, in a document sent out to doctors by the ME Association stated “ *the dominant clinical feature of profound fatigue is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis....the patient is often referred for psychiatric opinion. In my experience this seldom proves helpful and is often harmful*”. [ref: FOR YOUR DOCTOR: Myalgic Encephalomyelitis: A Baffling Syndrome with a Tragic Aftermath. A.Melvin Ramsay. ME Association 1981].

Without doubt, since the advent of the Wessely School of psychiatrists, this advice has been spurned and patients with ME/core CFS have been forced to submit to CBT and exercise regimes regardless of the severity of their condition, often in pursuit of claiming necessary state benefit. It must be recalled that a summary of the four separate surveys commissioned by Patient Groups on the CMO's Working Group found that **48% were harmed by the use of graded exercise therapy and 16% were not helped at all by graded exercise, and that 22% were harmed by using CBT, whilst 55% were not helped at all by CBT**. Advisers to the 25% ME Group for the Severely Affected have taken the Opinion of a distinguished, well-respected and influential Leading Counsel on the issue of CBT and graded exercise regimes in ME/core CFS. That Opinion contains the following legal advice:

*“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 in view of the clear division of medical opinion.*

*“It is of course open to patients, their parents, their guardians, their next of kin to seek Judicial Review of any proposed treatment on the facts and circumstances of a particular case”.*

A copy of the final CMO's Report on CFS/ME will be put before this same Leading Counsel for further legal opinion.

**Page 80: Online Annexes: OA6: Management of CFS/ME: Evidence-based approaches to follow.** Although we have not yet seen OA6, given the extent of inaccurate (indeed false) claims that CBT and graded exercise are the best “evidence-based” approaches to the management of CFS/ME, in anticipation that OA6 will advise such management approaches, we repeat our observation that CBT and graded exercise regimes **do not meet the necessary criteria to qualify as “evidence-based medicine”**. Our concerns over this aspect have been put before the Chief Medical Officer himself and he has personally responded (by letter dated 6<sup>th</sup> June 2001) that we make “some very important points” in our submission, which he intends to take up with the Committee.

**Page 83: Online Annex 4 (OA 4): General concepts and philosophy of disease  
(Professor Pinching)**

**Terminology:** *For...some patients with established disease, any name that has been applied will understandably become incorporated into their lives and belief systems”.*

In a previous submission to the Working Group [ *Matters of Continuing Concern, 9<sup>th</sup> March 2001*] we have pointed out that it is not a matter of a particular name becoming incorporated into a patient’s “belief system”: it is a matter of recognising that the term “ME” is known to represent a particular constellation of signs and serious symptoms which are not contained in the case definition of “CFS”. It is also a matter of accepting the need not to equate one specific syndrome with another syndrome of the same title when the two do not share all the clinical features. In particular, if the CMO’s Report uses the amalgamated term of CFS/ME, then the Report must accurately reflect the full spectrum of symptoms found in both ME and CFS and not those of only one subgroup (the psychiatric subgroup) of CFS.

**Subgroups:** *“On present evidence, this question may be considered a matter of semantics and personal philosophy rather than a matter of established fact”. We reiterate the point that international opinion is unequivocal about the need for attention to be given to the existence of subgroups [see our submission Matters of continuing concern dated 9<sup>th</sup> March 2001, pp 11-13].*

29<sup>th</sup> June 2001