RESTRICTED POLICY STATUS

OBSERVATIONS ON CHAPTERS 4 & 5 OF CMO'S DRAFT REPORT ON CFS / ME DATED 2 APRIL 2001 SUBMITTED BY THE 25% ME GROUP FOR THE SEVERELY AFFECTED

Chapter 4: Diagnosis of CFS/ME

Despite its title, this draft has virtually nothing to do with ME and has little bearing on patients who suffer from ME.

Perhaps not surprisingly, the author(s)' name has been withheld: this chapter reflects such lack of knowledge of ME / core CFS as to render it almost meaningless. It disregards so much that is well-known about diagnosing ME that it is hardly worthy of serious consideration. In our view, not only is it inane; it is an affront to medical science.

Some particular illustrations deserve special mention.

Page 1, para 2: *"there is no current validated test for the illness"*

Whilst it is true that there is no current single, definitive test for ME / core CFS, such a statement implies that there are no tests for the condition. In our view, this is disingenuous and it is untrue. There are tests which enable a diagnosis of ME / core CFS to be made with reasonable certainty.

References have already been provided and are readily available.

Immune abnormalities follow a recognisable, reproducible and consistent pattern, with clear evidence of an immune activation state.

There is objective evidence of brain impairment in the majority of patients which is compatible with a viral encephalitis. Patients show a particular pattern of hypoperfusion of the brain stem and this brain perfusion impairment provides objective evidence of central nervous system dysfunction. Brain imaging studies on ME / core CFS patients have shown that more areas of brain are involved in task-solving than in controls.

Cognitive dysfunction follows a distinctive and unusual pattern.

Research has clearly shown that sufferers show a significant reduction in all lung function parameters tested.

The endocrine system is uniquely disrupted in ME / core CFS: there is an abnormality of adrenal function and CT scans have shown that both the right and left adrenal glands are reduced by 50% when compared with controls. A key feature of ME / core CFS is the demonstrated defect in HPA axis function and patients are severely limited by the loss of dynamic hormone responses.

There is a significant dysregulation of the RNase L antiviral pathway.

There is a universally acknowledged dysfunction of the central, autonomic and peripheral nervous systems.

There are well-documented cardiac anomalies.

Vascular anomalies are well-documented in the literature.

There is significant involvement of the liver, pancreas and gut.

There is documented evidence of post-exertional muscle fatiguability, with a prolonged recovery time.

There is evidence from the Centres for Disease Control in Atlanta that patients with ME / core CFS can be differentiated by different gene expression and that patients can be separated from controls by this means. Further research has shown that immune dysfunction is not genetic (and must therefore be *acquired*).

There are a number of clear, unequivocal physical signs.

Page 1, para 2: *"One of the commonest complaints of adults in the early stages is 'tired all the time' ".*

This may indeed be the case in some subgroups of CFS, namely psychiatric patients with a diagnosis of TATT (tired all the time) but it is not the case in ME, where the over-riding complaint is of post-exertional muscle fatiguability; this is quite different from TATT.

Page 2, para 2: *"Where….CFS /ME is one of the possible diagnoses, only a limited set of investigations are appropriate"*

This is a direct lift from the 1996 much criticised and psychiatrically biased Joint Royal Colleges' Report and it is wholly unacceptable advice in the framework of the CMO's report. It is in complete contradiction to the advice given at the Fifth International AACFS Conference held in Seattle in January 2001, where world-class experts specifically demonstrated that basic laboratory testing is not sufficient for such patients. The point was made that these patients require advanced immunological and other testing.

In the light of this knowledge (which is freely available on the Internet), such deliberate failure to implement, indeed to curtail, necessary testing is liable to lead to indefensible litigation.

Page 2: *"Using existing diagnostic criteria"*

The existing diagnostic criteria relate to hetergeneous CFS (which specifically includes psychiatric disorders) and not to ME. No matter how insistently the authors of this CMO's report try to claim that ME and CFS are synonymous, people will not be bludgeoned into acceptance of something which is so intrinsically erroneous and which can be shown to be nonsense. Patients worldwide are now so well-informed, so by repeatedly ignoring the evidence, the authors merely succeed in bringing yet more opprobrium upon themselves and upon those they seek to influence.

Page 6 *" Diagnosis of CFS/ME in children. .... loss of schooling can be considered a proxy diagnostic indicator"*

In medicine there is a requirement for rigorous scientific standards of evaluation. Children may be absent from school for all sorts of reasons, some social and some medical. It is incumbent upon medical practitioners not to rely on any "proxy diagnostic indicator" and never to make facile and unsustainable assumptions as to why a child might be missing school.

Page 6: *"The diagnostic process"*

No mention is made of the importance of screening for viral antibodies as early in the diagnostic process as possible (because levels fall off after three months).

Page 10: *"Referral for specialist opinion"*

It is, in our view, fallacious to assert that much if not all of the diagnostic process can be satisfactorily undertaken by the GP. This is not in accordance with patients' experience. Moreover, without diagnostic support from a hospital consultant, patients are ineligible for state and insurance benefits.