

Mr Will Scott
Long Term Conditions Unit
Scottish Government Health Directorates
St Andrew's House
Regent Road EDINBURGH
EH1 3DG



The Scottish Neurosciences Council
c/o Neurosurgery Network Office
Department of Clinical Neuroscience
Western General Hospital
Crewe Road EDINBURGH
EH4 2XU

23 June 2010

Dear Mr Scott

Scottish Good Practice Statement on ME-CFS: Initial Comments from Scottish Neurosciences Council

In response to the circulated draft of the Good Practice Statement on ME-CFS we wish to document some initial comments from the Scottish Neurosciences Council. We think that in general terms guidance on the management of ME-CFS is to be welcomed and we recognise it as a real and disabling condition. We also recognise the considerable amount of work that the various patient representatives have put into this document thus far. However, with reference to the WHO classification G93.3 *Post Viral Fatigue Syndrome* including *Benign Myalgic Encephalomyelitis* under *Disorders of the Nervous System* we consider some expert comment from the SNC to be appropriate, particularly as we have a number of concerns about some technical aspects of the circulated version of the Good Practice Statement.

- In section 2, under the heading 'Criteria', at point 5 on page 7, the statement says that 'ataxia, muscle weakness and fasciculations are common'. This seems to be drawn from the Canadian consensus document. The Council takes the view that the 'hard' neurological signs of ataxia or fasciculations never occur in ME-CFS. Where these signs do occur, they have very specific clinical implications, and would indicate a diagnosis such as Motor Neurone Disease (MND) or similar. There is a strong concern that by including these symptoms in its core description of the condition, the statement would lead to misdiagnosis both of those with those with ME-CFS and with other unrelated neurological diseases. We would suggest there is no advantage in departing from the NICE ME-CFS Guideline (2007) in terms of disease definition.
- By including comment on such untested techniques as mitochondrial testing the document gives them credence: the description of this in section 5, page 25, is not sufficiently sceptical. In particular, it doesn't mention that treatment is offered on the basis of the tests without any involvement of the person's GP, that there has never been any independent replication of the findings and that the only published results are in a 'pay-to-publish' internet journal in a study conducted by the purveyors of the test.
- The statement is too dismissive of the Cochrane and NICE work, which indicate that CBT and GET are, at present, the only treatments known to be effective (at Grade 1 evidence level) - albeit not in all patients. It may have been beneficial to see if it was possible to gain preliminary data on the acceptability and safety of such treatments from the PACE study (ie a randomised design) rather than relying on survey data, a technique which is highly liable to response bias.

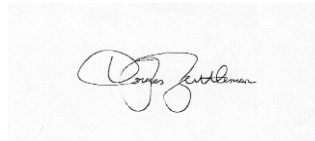
- In terms of pharmacological management, the statement simply lists a range of largely untested treatments, but gives the GP no real assistance about what he or she should be doing. The comment on thyroxine (page 20) is an example of the sort of approach, which we think this section should be adopting. By contrast, the statement on nimodipine is mildly enthusiastic towards an untested treatment; the SNC understand the theory behind such a recommendation relates to some results from SPECT scanning studies, but it appears to misunderstand the principles behind such imaging techniques.
- We think much more guidance is need on a triaged approach to tests and investigations
- In general terms, the statement does not dovetail well the NHS QIS Clinical Standards for Neurological Conditions (2009), which are much more about the need for integration of all forms of treatment, including psychological aspects.

We hope these comments will be of some help in taking this valuable piece of work forward.

Yours sincerely,



President,
Scottish Neurosciences Council



Mr Douglas Gentleman
Honorary Secretary,
Scottish Neurosciences Council



Dr Alan Carson
Convenor of Working Group
Scottish Neurosciences Council