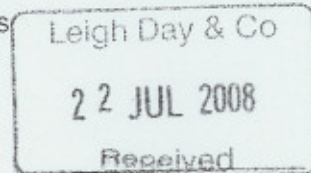




HOUSE OF COMMONS

LONDON SW1A 0AA

Mr Jamie Beagent
Leigh Day & Co Solicitors
Priory House
25 St John's Lane
London
EC1M 4LB



Our Ref: SHOR01001/01081040/jb

21 July 2008

Dear Mr Beagent

Re: Douglas Fraser & Kevin Short v NICE – Case Number: CO/10408/2007

I have been Member of Parliament for Norwich North since 1997 and have a background and interest in science and health issues: I taught in the School of Biology at the University of East Anglia from 1965, was Dean from 1991 to 1997 and was made Honorary Professor in 2003; I served on the House of Commons Science & Technology Select Committee and was its chairman from 2001 to 2005; In 2005 I established and chaired a cross-party ME/CFS science inquiry with members from both Houses of Parliament, *The Group on the Scientific Research into ME* (GSRME), that reported in November 2006; The GSRME was a NICE Stakeholder; I am currently Secretary to the All Party Parliamentary Group on ME.

I am writing to support Kevin Short and Douglas Fraser in the Judicial Review of the National Institute for Health and Clinical Excellence (NICE) Guidelines for ME/CFS. I am unhappy with the current NICE Guidelines on ME/CFS. I am also concerned that the composition of the Guideline Development Group (GDG) was unbalanced and unrepresentative and consequently excluded biomedical expertise.

The current guidelines recommend cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as the 'clinically excellent' first choice treatment for most patients; however the guidelines understate the potential harm with graded exercise. The study by A Peckerman, J Lamanca *et al*, for example, found that in severe cases ME/CFS patients may also develop reduced circulation which may lead to heart conditions: so graded exercise may be potentially fatal for them. There is a considerable body of international peer-reviewed evidence and expert opinion giving some indication that graded exercise therapies may also cause harm to patients other than just the most severely affected. This suggests further biomedical research on such matters is urgently required. That the GDG did not adequately consider the large body of existing international evidence means they were in no position to make the recommendations they did on the use, efficacy and safety of such therapies.

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NICE claims that both CBT and graded exercise therapy are supported by an adequate evidence base, however, the GDG relied on a very small number of controversial randomised control trials (RCTs). The patient selection criteria for participating in the trials were too wide and therefore allowed non-ME/CFS sufferers to participate. It is also misleading to refer to CBT & GET as 'treatments' of 'choice'. They cannot properly be described as treatments, since, as NICE admits, they do not address the core pathology of ME. Neither is there effective choice given that many patients will be denied much of the knowledge they need to make informed decisions and there is little alternative to CBT/GET on offer in the NHS. CBT/GET have also been rejected by ME patient charities in the UK. The NICE Guidelines give the false impression, to doctors, politicians, and the MRC, that effective treatments are available for ME patients. NICE would do better to honestly admit that their core therapy recommendations are not properly evidence-based, and to use this admission as the starting point for an adequately-funded search for a cure. We should not forget that ME patients have a legitimate right to aspire to a cure. Far too many doctors appear to have lost sight of that objective.

That NICE did not adequately take into account the general international biomedical evidence base was highlighted by the GSRME committee of senior parliamentarians I chaired in 2005-6 who were concerned with both the psychiatric dominance in the current UK ME research programmes and patient selection criteria they use. I am therefore disappointed that the NICE GDG did not adopt or endorse high quality internationally recognised patient selection and diagnostic criteria such as the Canadian Criteria even though the latter were mentioned in the Guideline.

I am also concerned that the NICE GDG did not properly fulfil its remit and did not properly adhere to the internationally accepted high standards of guideline development such as the European Union AGREE instrument of which NICE is a signatory. The NICE GDG also failed to endorse the World Health Organisation definition of ME/CFS as a neurological disorder despite the fact the Department of Health and Government Ministers have repeatedly confirmed that they do agree with this classification. I do not believe that the NICE CFS/ME Guidelines are fit for purpose.

Yours sincerely

A handwritten signature in black ink that reads "Ian Gibson". The signature is written in a cursive style with a large initial 'I'.

Dr Ian Gibson
MP for Norwich North
Secretary to the All Party Parliamentary Group on ME