

This document contains live links highlighted in blue.

25 October 2007

Execrable AfME Charity CEO Sir Peter Spencer Exposed

The AfME Charity Response **[Judicial Review, Legal Appeal](#)** **CFS/ME NICE Guidelines**

The One Click Group publishes today the response of [Sir Peter Spencer](#), CEO of the UK charity Action for ME (AfME) to the Legal Appeal for Judicial Review against the CFS/ME National Institute for Health and Clinical Excellence (NICE) Guidelines.

Firstly, three things should be noted:

- 1.** The vast majority (eight in number) of the major UK ME/CFS charities have publicly declared these Guidelines as Unfit for Purpose. Only two of the ME/CFS charities have announced their support: AfME and AYME (children's charity), which is to all intents and purposes the junior branch of AfME. AfME is therefore very much on its own with this.
- 2.** AfME has been closely involved with supporting the psychiatric abuse of ME/CFS labelled patients for many years as the material evidence contained in [The AfME Dossier](#) published by One Click in 2004 so clearly shows. This charity is stuffed to the gills with psychiatric lobby/government grants and therefore in order to maintain its vested interests income stream, it must support these Guidelines by default.
- 3.** AfME has purposefully refused to hold an Annual General Meeting that has involved its members/subscriber for the last eleven years, since 1996. It has therefore completely disenfranchised the patients' community and its strategy does not reflect the views of its members/subscribers. Only a charity in the United Kingdom would be permitted to perform this type of completely undemocratic malfeasance. (Members of UK Parliament take note).

AfME Charity Refuses Support

The UK charity Action for ME (AfME) has chosen not to support the One Click Group's Legal Appeal for the Judicial Review of the CFS/ME NICE Guidelines. See the [AfME/One Click Correspondence](#).

AfME has released statements and a written response to The One Click Group revealing an unacceptably weak stance towards correcting the flaws in the Guidelines.

This is in spite of AfME's own admissions that the [CFS/ME NICE Guidelines](#):

"could have been better in some important areas"

and that the Guidelines placed:

“undue emphasis on two treatments - cognitive behavioural therapy (CBT) and graded exercise therapy (GET) - for which the underlying evidence is inadequate and unrepresentative. Many patients have reported little or no benefit.”

“that the GDG could not agree to recognise the World Health Organisation’s classification of M.E. as a neurological illness”.

“the summary guideline does not convey or reflect the impact which the illness can have on the lives of those people who are most severely affected by M.E.”

Effectively AfME has admitted in public that the Guidelines do not really take patients any further forward. The Guidelines do not acknowledge that ME/CFS is an organic illness, still recommend exercise, anti-depressants and behavioural therapies and do not properly reflect the impact on the life of the sufferer. How is this any different to the situation five or ten years ago?

ME/CFS is acknowledged to be an organic neurological illness by the World Health Organisation (WHO ICD-10 G93.3). This is supported by the research in over 2,000 research publications and NICE have chosen to ignore almost every single one. It maintains that ME/CFS excludes organic illness in spite of continual findings of live infections and numerous biomedical abnormalities in such patients. While the CFS/ME NICE Guidelines maintain the ‘diagnosis of exclusion’ stance they are of no value to patients whatsoever. The only mention of infections in the NICE Guidelines is that testing is left up to the doctor’s discretion and that the presence of an infection in ME/CFS patients would be seen as ‘exclusionary’ rather than causal.

How AfME could therefore view the Guidelines as ‘a landmark in the mainstreaming of M.E. as a legitimate illness’ is utterly ludicrous.

A diagnosis of exclusion is effectively a psychological diagnosis – and in fact [Professor Simon Wessely](#), leader of the UK psychiatric lobby that has done so much damage to us all, has gone on record recently to state that labels such as ‘Fibromyalgia’ (which up to 75% of ME/CFS patients have according to the [ME/CFS Canadian Guidelines](#)) are simply ‘euphemisms’ for psychological disorders and depression. See [Unum CMO Report 2007](#)

Effectively the CFS/ME NICE Guidelines have legitimised the use of such ‘euphemisms’ to fool patients into believing that they have been properly diagnosed and that they will receive appropriate treatments, when in fact the doctor will believe from these Guidelines that they have deep-rooted psychological and behavioural problems contributing to or causing their symptoms.

If anyone is in doubt – then compare the following

Professor Simon Wessely, [Unum CMO Report 2007](#), ‘Why and when do doctors collude with patients?’

“Support is given. Antidepressants are prescribed, although rarely for ‘depression’, but for analgesia or sleep disturbance. Rest, but in moderation, is encouraged, and linked to some form of regular activity. “Collusion” some might and do say, but it can promote rehabilitative or psychological treatments which if taken head on, would only have led to offence.”

And from the [CFS/ME NICE Guidelines](#):

"1.6.3.2 Prescribing of low-dose tricyclic antidepressants, specifically amitriptyline, should be considered for people with CFS/ME who have poor sleep or pain"

AfME has allowed NICE and the psychiatric lobby to rubber stamp ME/CFS as nothing more than a non-diagnosis and a euphemism and Sir Peter Spencer, AfME Chief Executive, has absolutely no intention of challenging this situation. He has put it in black and white that he will not donate a single penny of his charity's funds to the [Judicial Review Legal Appeal](#).

Instead he believes that doctors simply need 'training' to implement the NICE CFS/ME non-diagnosis. This charity receives almost £1 million in funds according to the 2005/06 Annual Report (the last available):

"The total income for 2005/06 was £955,883 which is an increase of £173,977 from the previous year."

This AfME charity, if it had wanted, could have paid outright for a Judicial Review and patients should remember this. There were no financial obstacles in its way but regardless it chose not to correct the important areas, which in its own words could have been so much better. Instead, it has been left up to patients to give up their precious funds to try to ensure that this Judicial Review goes ahead.

The UK ME/CFS Charities

In considering AfME's position, perhaps the ME/CFS community would like to benchmark its progress against that of Multiple Sclerosis, Amyotrophic Lateral Sclerosis (ALS), Alzheimer's, Parkinson's, Epilepsy and Lyme Borreliosis. Look how hard THESE charities have worked for their patients! How do you think these patients would react if their charities had been happy to accept a 'hysterical paralysis' or 'sexual repression' explanation for their dreadful diseases? If THEIR charities hadn't fought, this is where they would be.

Why is it then that ME/CFS has such a large patient group, with such severe symptoms (compared in gravity to cancer, polio and HIV/AIDS) and yet it cannot get its neurological status recognised?

The answer is that your charities are just not working hard enough for you – if at all - and now given the golden opportunity to make amends they turn their backs on you.

Ask yourself, is this good enough? And if the necessary funds for this Judicial Review are not collected who is to blame? A charity pulling in £1 million/year, who would not give 1-2 % of its income to support a legal challenge that has the power to really place a 'landmark in the mainstreaming of M.E. as a legitimate illness'.

We refer you to the published AfME documentation below:

From the AfME Web Site (referred to in Sir Peter Spencer's letter to One Click)
AfME News
[NICE guideline amended \(press release\)](#)
22 August 2007

One Click EXTRACTS

National Institute for Health and Clinical Excellence (NICE) has published its guidelines on the diagnosis and management of M.E. (myalgic encephalomyelitis / encephalopathy) or chronic fatigue syndrome today, 22 August 2007.

The trustees are disappointed to note that the guidance still places undue emphasis on two treatments - cognitive behavioural therapy (CBT) and graded exercise therapy (GET) - for which the underlying evidence is inadequate and unrepresentative. Many patients have reported little or no benefit from CBT and others have experienced seriously adverse effects from GET.

They are also disappointed that the GDG could not agree to recognise the World Health Organisation's classification of M.E. as a neurological illness.

In addition, the summary guideline does not convey or reflect the impact which the illness can have on the lives of those people who are most severely affected by M.E.

Sir Peter Spencer, Chief Executive of Action for M.E., added:

"When the draft guideline was published last September, Action for M.E. and other patient groups were united in their belief that CBT and GET should not be recommended as 'treatments of first choice'. NICE has responded by removing this phrase but CBT and GET remain. As a result, aspects of the guideline are problematic."

Despite the AfME charity's pronouncements, it continues to sanction and uphold the psychiatric abuse of ME/CFS labelled patients and will not donate one single penny from its inflated coffers to assist with Judicial Review of the Guidelines.

For all those ME/CFS patients worldwide who consider the behaviour of this AfME charity for many years and particularly now at this very important legal time for patients to be execrable, herewith the contact details for you to lodge your complaints.

What choice have patients been given but to communicate in this way since they have been utterly disenfranchised by this charity for the last eleven years? (UK Members of Parliament on the One Click Newsletter distribution list, please note this important fact).

Contact these AfME Charity Officers to make them do their duty to patients now.

George Armstrong - AfME Chairman
geasa@onetel.com

Sir Peter Spencer - AfME CEO
peter.spencer@afme.org.uk

Roy Cheng - Spencer's Assistant
roy.cheng@afme.org.uk

Patricia Taylor - Previous AfME Chairman
trish.taylor@afme.org.uk

Action for ME (sic AfME)
Third Floor
Canningford House
38 Victoria Street
Bristol
BS1 6BY

Tel: 0845 123 2380 / 0117 9279551
Fax: 0117 9279552

What the AfME charity has done in October of the year 2007 may well go down in history as the biggest ME/CFS own goal of all time and it looks as though you have AfME to thank for it.

The One Click Group