

## Concerns about the RSM Conference on 28<sup>th</sup> April 2008 on “CFS”

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There is international concern about the forthcoming conference on “CFS” (chronic fatigue syndrome) to be held at the Royal Society of Medicine (RSM) on 28<sup>th</sup> April 2008 because there can be little doubt that the conference is a “Wessely School” initiative that is intended to promote the psychosocial model of “CFS” and to “educate” GPs accordingly. The psychosocial model denies the reality of myalgic encephalomyelitis as a distinct neurological disorder and subsumes it within “CFS/ME” as a behavioural disorder.

Such is the concern that many representations have been made to the Dean of the RSM, Dr John Scadding. People have expressed dismay that the Royal Society of Medicine should be providing a platform for a group of psychiatrists who are committed to eradicating ME as a distinct medical disorder and who persistently dismiss the substantive evidence that it is not a primary mental disorder but a serious and complex multi-system organic disorder.

In addition to countless postings on the internet, a postcard campaign has been organised for people to write to the Dean; there have been letters to the press; a demonstration outside the RSM has been organised to take place on the day of the conference, and one medical practitioner (himself a Physician-in-Waiting to the Royal Family) has written to Her Majesty the Queen suggesting that such is the outrage, she may wish to consider withdrawing the Royal patronage from the Society. Most of the UK ME/CFS charities have expressed profound disapproval of the undeniable psychiatric bias of this RSM conference.

In response to some of those publicly expressed concerns, the Chief Executive of the RSM, Mr Ian Balmer, wrote on 23<sup>rd</sup> April rejecting the “supposed bias” of the conference on “CFS”: *“Our agenda was drawn up to reflect current thinking on its diagnosis and treatment, as outlined in the NICE guidelines. The content of the meeting is well-grounded in evidence-based medicine and has been planned by a broad-based academic planning group”*.

This has further fuelled the international concern, because innumerable people (including not only well-informed patients but also clinicians and medical scientists who have direct knowledge of ME/CFS) believe it is simply untrue that the conference content is *“well-grounded in evidence-based medicine”*.

It will be known by some in the ME community that there is more than one application for Judicial Review of the NICE Guideline currently before the High Court in London.

One application for judicial review has been brought by two ME sufferers which is supported by expert evidence from Professor Malcolm Hooper and Dr William Weir. The individuals bringing the case are represented by a premier Public Law firm, Messrs Leigh Day & Co in London. Leigh Day & Co are leaders in the field of claimant public law and recognised as having particular expertise in the field of health care, being ranked as number one in Chambers' Directory (the contact being Jamie Beagent). They have submitted substantial evidence to the High Court that the NICE Guideline was not properly founded on "evidence-based medicine" -- and thus by implication, the content of the RSM conference cannot be. In a recent Order, the High Court (Mr Justice Stanley Burnton) recognised that despite NICE's assertions that the legal case is without merit, the evidence is so extensive that the Court will hold a day's hearing to consider the case in more detail. The Order states: "*The Court is usually cautious to intervene in matters involving medical or other scientific judgment. Be that as it may, the evidence is sufficiently substantial for the Court to be assisted by oral submissions*".

It will be recalled that Professor Hooper and Horace Reid were amongst the first to expose the inadequacy of the York Systematic Review upon which NICE relies for its so-called "evidence" of the efficacy of its recommended management strategy ([http://www.meactionuk.org.uk/FINAL\\_on\\_NICE\\_for\\_Gibson.html](http://www.meactionuk.org.uk/FINAL_on_NICE_for_Gibson.html)).

There is in existence a letter dated 17<sup>th</sup> April 2008 from The Scottish Government's Healthcare Policy and Strategy Directorate Healthcare Planning Division (reference 2008/0010027OR) signed by Fiona McGrath of the Long Term Conditions Unit. It states, amongst other things: "***One of the most effective ways of improving services for long term conditions such as CFS/ME is by developing clinical standards. NHS Quality Improvement Scotland (NHS QIS) is working on clinical standards for neurological conditions, including access to investigations by neurologists. NHS QIS expects the draft standards to be ready for consultation in autumn 2008, with publication of the final version likely to take place in the summer of 2009***".

The whole two page letter is about CFS/ME, so questions arise as to how and why "CFS/ME" is now officially regarded as a chronic neurological disorder under the auspices of the Long Term Conditions Unit in Scotland, but as a behavioural disorder under the aegis of mental health policy by the RSM, the Medical Research Council (MRC) and NICE in England?

A copy of the letter has been sent to the Dean of the RSM asking him to explain this discrepancy, but so far there has been no acknowledgement or response.

This is all the more pertinent in that it was the same Dr John Scadding who on 17<sup>th</sup> September 2007 attended a conference in London entitled "Should patients Tell Researchers What To Do? If so, How?" that was arranged by the James Lind Alliance in conjunction with the Association of Medical Research Charities; the meeting had as its main topic the importance of expert patient input into medical research and how this can best be achieved. It was Dr Scadding who chaired the afternoon Working Group session to establish an effective way of implementing patients' input. One question that was put

before the panel was: “*What would panel members suggest could be done to ensure that major UK funding and other Institutions --- like the Medical Research Council, NICE, the Centre for Reviews and Dissemination at York, the National Health Service and the Department of Health --- take more notice of what patients say?*”. There can be no doubt that this issue was raised and that Dr Scadding was fully aware of the immense concerns amongst ME/CFS patients, so it is all the more disturbing that he has apparently agreed not only to host this controversial conference at the RSM, but that he is also scheduled as a speaker and co-chair of the event. As a result, it is difficult to reconcile his apparent sympathies with patients’ needs to be heeded with his support for and involvement with a conference to promote the psychiatric model of “CFS/ME”.

A letter setting out concerns about the RSM conference has also been sent to the Parliamentary Under Secretary of State for Health (Mrs Ann Keen MP), drawing her attention to the widespread disquiet about the forthcoming RSM conference and pointing out that numerous large-scale patient surveys have shown that NICE’s management regime of cognitive behavioural therapy (CBT) is largely ineffective and that graded exercise therapy (GET) is potentially harmful, and that it is therefore inappropriate for the RSM conference to promote such a regime. Her attention was drawn to the substantial international evidence of demonstrable and replicable biomedical abnormalities that Wessely School psychiatrists continue to ignore or dismiss. It will be recalled that at the All Party Parliamentary Group on ME that was held on 22<sup>nd</sup> January 2008, Mrs Keen went on record saying that she believed ME/CFS to be a neurological disorder.

A copy of the letter from the Scottish Government was also enclosed with the letter to Ann Keen MP, requesting that she address the discrepancy between the Scottish and English government’s approach to the same disorder that Dr Scadding has so far failed to address.

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**25th April 2008**

**A Follow-up to “Concerns about the RSM Conference”**

**Margaret Williams**

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