On 28 April The Royal Society of Medicine is holding a conference on “Chronic Fatigue Syndrome”

The conference programme states:

“…The aim of the meeting is to take a broad look at chronic fatigue syndrome, examining its nature and definition, pathophysiology, epidemiology, clinical assessment and diagnosis, the patient perspective, and various approaches to treatment. This is a scientific conference and there will be an emphasis on an evidence-based approach throughout […] Those attending the meeting will gain understanding of the various aspects of CFS being discussed, and be better able to help people suffering from this disabling condition. The conference is intended for all health professionals who are involved in the assessment and treatment of those with CFS…”

Read about the concerns surrounding this conference and full copies of patient organisation position statements here: http://readmeukevents.wordpress.com

Professors Wessely, White, Bhui and Hotopf were members of the RSM’s Planning Committee for this conference and there is a very heavy psychiatric/psychological bias to the presentations. Speakers include Professors Simon Wessely (KCL), Peter White (BARTS, PACE), Matthew Hotopf, Rona Moss-Morris (CBT/GET), Chris Dowrick (FINE Trials) and Dr Anthony Cleare (IoP). Session chairs include Professor Mansel Aylward (Unum Provident Centre for Disability) and Richard Baker (NICE).

The conference is for members of the RSM and for health care professionals only. There are no seats for members of the public and the RSM has told me that the meeting is not open to the Press. The RSM has yet to confirm to me who initiated this conference, whether it is sponsored – and if so, by whom. NICE? UNUM?

Conference programme PDF: http://rsmcfsprogramme.notlong.com

AfME’s new CEO, Sir Peter Spencer, is also a speaker at this meeting – representing “the patient perspective”. Can AfME be trusted to properly represent us?

Sir Peter says:

“It is better to have balanced debate than for different factions to exist in parallel worlds, where they do not engage in dialogue or work together to increase our understanding of this debilitating illness. On this occasion I will have a great opportunity to set out the serious concerns that we and our members have about the way in which evidence-based
principles have produced very dubious outcomes when only a very tiny amount of so-called “gold standard” data is available from randomised controlled trials…”

But other ME patient organisations and many within the ME community, itself, have voiced concerns that AfME is prepared to take part in this event, at all.

The ME Association says:

“The ME Association fully shares the concerns of a growing number of our members who have been contacting us about the strong psychiatric/psychological bias to the presentations that will be given to a meeting on CFS at the Royal Society of Medicine on April 28…”

The 25% ME Group says:

“We are taking a position of no compromise when it comes to the Royal Society of Medicine Conference on CFS…As chairman of the 25% ME Group, I am very distressed to see any ME charity advertising, promoting and supporting the RSM April psychiatric conference on “CFS”…I also feel there is no justification for the CEO of AfME to be speaking at the RSM conference, as I believe it will not benefit patients with ME and implies patient-backed validity to psychiatric involvement in ME…”

The Young ME Sufferers Trust says:

“…The Trust does not consider that involvement with such a conference can do other than lend further credibility to those who already have undue influence on treatment for children with ME…Families tell us that their children’s condition is either not being helped, or is being harmed by such dogma.”

RiME (Campaigning for Research into ME) says:

“RiME disassociates itself from the above meeting. This type of forum is not only unhelpful in that it enmeshes a neuro-immune-endocrine-vascular disease (ME) with a range of other conditions, some of which might respond to psychiatric/psychological models of treatment. That an organisation which purports to represent ME patients’ interests would participate shows the depths to which it has sunk. Instead of fighting the ME patient’s corner, it cosies up to the establishment. I wonder why? Shame on it.”

Sir Peter calls for dialogue and debate.

We’ve been talking to the Psychs for years: they’re not listening.

What we need is funding for biomedical research: not CBT/GET.

What we need are care packages: not Psychs.

A demonstration is planned for the afternoon of Monday, 28 April outside the RSM

RSM Protest | 28 April 2008 | 1 Wimpole Street London W1G OAE | 1pm to 6pm
Enquiries to demonstration Organiser: Gus Ryan: Email: creamcrackereduk@yahoo.co.uk

It’s hoped that as many as possible will join the demo outside the Royal Society of Medicine – if only for an hour or so. But if you’re not able to attend and if no-one can come on your behalf, can you please send a postcard to the RSM, instead?

“On a Postcard, please” campaign: http://rsmcfspostcards.notlong.com
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The CFS Conference Planning Committee was chaired by Dr John Scadding, Dean of the RSM and a consultant neurologist at the National Hospital, Queen Square, London. Please write to the Dean and tell him what’s wrong with this conference.

The influence of Wessely and White impacts on the quality of care, services and the financial support that ME sufferers receive and the treatments and tests they have access to, both here in the UK, and internationally – can you please send a postcard to the RSM even if you live outside the UK?

An A6 or 4” x 6” piece of card or stiff paper will do if you don’t have a postcard to hand.

**Address your Postcard to:**

Dr John Scadding, Dean  
Royal Society of Medicine  
1 Wimpole Street  
London W1G 0AE

On the back, write, print or paste your message.

You might want to focus on the psychiatric/psychological bias to the Planning Committee and the speakers they have selected or maybe include an issue such as research funding, CBT/GET, the inadequacies of CFS Clinics, UNUM or NICE. Or you may want to raise questions about the planning and development of the conference, itself, and whose initiative this meeting was.

Keep it courteous and constructive. Don’t forget the stamp!

If you’re not up to writing please ask someone to write for you.

If you’re not able to get out, please ask someone to post your card to arrive before Monday 28 April. If you’re sending from outside the UK please allow extra time for delivery.

In the run up to this most contentious conference I urge as many of you as possible to take the opportunity of making the RSM aware of your concerns.

**We’ve got just three weeks until 28 April, can hundreds of us both here in the UK, and internationally, let the Royal Society of Medicine know what we think?**

Thank you!

**Suzy Chapman**  
me.agenda@virgin.net

“On a Postcard, please” campaign:  http://rsmcfspostcards.notlong.com

Read ME UK Events site:  http://readmeukevents.wordpress.com

Please note that the “On a Postcard, please” Campaign and the “Squeeze” graphic are initiatives independent of the RSM demonstration being organised by Gus Ryan. All enquiries about the Postcard Campaign and the Read ME UK Events site should be addressed to Suzy Chapman.