

ME Research (UK)

Eileen Marshall & Margaret Williams

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ME Research (UK) started in 1987 as an information service for lawyers who found themselves engaged in the litigation process but who knew almost nothing about ME. Its purpose was to disseminate published information about ME so that Claimants would not be unfairly disadvantaged by ignorance on the part of those upon whom they were obliged to rely.

It was founded at the suggestion of staff at the British Library in Boston Spa, West Yorkshire, and it was they who coined the title.

With the increasing dominance within the medico-legal system of the psychiatric lobby and the consequently increased need for correct and accurate information, of necessity, those associated with ME Research (UK) broadened their perspective to include comments on what was perceived by many as undue reliance on the views of psychiatrist Simon Wessely and his colleagues (known colloquially as the “Wessely school”) and to put the views of the psychiatric lobby into context by comparing them with published material that did not subscribe to those views.

With full permission, approval and cooperation of the British Library, the contact address for ME Research (UK) was c/o the BL’s address in Boston Spa, who agreed to forward any correspondence. That arrangement has worked for almost 17 years.

However, as from 29th September 2004 the arrangement has been terminated by the British Library.

This is because of a complaint received by the BL concerning an item commenting on Professor Wessely’s evidence to the Lord Lloyd Public Inquiry on Gulf War Syndrome (“Observations on Professor Wessely’s evidence to Lord Lloyd’s Public Inquiry into Gulf War Syndrome”. Eileen Marshall and Margaret Williams; 28th August 2004, available at www.meactionuk.org.uk/Further_Articles.htm). The item in question for the most part simply quoted from Professor Wessely’s own testimony to the Public Inquiry (and his evidence itself is available on the Public Inquiry website).

As we understand matters, the BL cannot be seen to be associated, however remotely, with any criticism of Professor Wessely’s views.

Consequently, the new management at the BL have withdrawn the facility offered to ME Research (UK) that has existed for the last 17 years.

Members of the ME community will no doubt recall that in 1994, Professor (then Dr) Wessely threatened the UK ME charity Westcare with legal action if an article written by us was not physically torn out of all copies of the CFIDS Chronicle before being distributed by Westcare throughout the UK. That article was called “The views of Dr Simon Wessely on ME: Scientific Misconduct in the Selection and Presentation of Available Evidence?” (CFIDS Chronicle, Spring 1994: 14-18). As in the case of the recent observations on

Professor Wessely's evidence to the Public Inquiry into Gulf War Syndrome, that article in CFIDS Chronicle merely collated and quoted from Wessely's own published works and, in the light of other published evidence on ME, asked what the lawyers advising the CFIDS Chronicle Editorial team considered to be legitimate and necessary questions about Dr Wessely's views on ME. However, being a small charity, Westcare's Director (Richard Sykes) could not run the financial risk of Wessely's threats of legal action so he capitulated and agreed to remove the article before distribution in the UK. People then complained that copies for which they had paid in advance had been defaced in the absence of any injunction requiring this to be done. None of the copies mailed directly from the US was similarly defaced and the article gained far more publicity than might otherwise have been the case, because the removed article was widely circulated by those who did receive it.

Finally, and on the same topic, members of the ME community might like to know that Dr Margaret Cook (who on 6th October 2003 wrote an article in The Scotsman that was critical of Professor Wessely – "ME sufferers have found enemy in Wessely – so they need friends") has since been relieved of her position as a regular columnist on The Scotsman.

In the UK, we are constantly being reminded by the Prime Minister that we live in a democracy and therefore have the right to freedom of speech, but does this exclude the ME issue?