

Information in the public domain which is of potential relevance to the ME community

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In recent years, medical and scientific research is increasingly funded more by organisations with commercial interests and less by Government, whereas previously such research was funded by Government departments through the various Research Councils. Now, however, industry-linked organisations (for example, the Wellcome Trust) fund as much research as the Medical Research Council: in March 1998 Sir Kenneth Calman (then Chief Medical Officer) stated that since 1991 the (Sainsbury) Linbury Trust had funded over £4 million for research into “chronic fatigue syndrome”. This has been a cause for concern because the Linbury-funded studies have looked at patients with on-going or chronic “fatigue”, not at those with ME or ICD (non-psychiatric) CFS and their studies mostly have a heavy emphasis on a psychiatric cause. Confusingly, the psychiatrists who authored these studies claim that their research *does* include those with ME / ICD-CFS (see the two Linbury Trust “Portfolios” on chronic fatigue, both published by the Royal Society of Medicine, one in 1998, the other in 2000).

Since 1996, David Sainsbury has donated £7 million to the Labour Party: in 1998 he resigned as Chairman of the Sainsbury’s supermarket chain to become Labour Minister for Science and is now Lord Sainsbury of Turville (not to be confused with his brother John, now Lord Sainsbury of Preston Candover). This made David Sainsbury the Parliamentary Under-Secretary of State for Science and Innovation, giving him responsibility for the Office of Science and Technology, together with the chemical and biotechnology industries, as well as all the Research Councils, including the MRC.

The Office of Science and Technology monitors all Government funding of research and controls official policy on the direction of that research.

Recently, Dr Diana Dunstan of the MRC claimed that the panel of experts appointed to advise Government about the direction of future research into “CFS/ME” consists of people who had not previously been involved in the field and who were “independent” and “fresh” to the subject. This was misleading in the extreme, given that Professor Alan McGregor of Kings College and Professor Philip Cowen of Oxford (both members of the MRC panel) have certainly co-authored papers on and been involved with “CFS” studies, and both men have links to the Linbury Trust. Professor McGregor, listed by the Trust as a “Member of the Linbury Advisory Panel on CFS”, has co-authored papers on CFS with psychiatrist Professor Simon Wessely and Professor Cowen (from Oxford, where both he and psychiatrist Michael Sharpe were based until Sharpe moved to Edinburgh) has co-authored papers on CFS in the BMJ with Sharpe.

It is necessary for the ME community be aware of the background of members of this particular MRC group, given that the CMO’s Working Group on “CFS/ME” was partially funded by the Linbury Trust and, more unusually and disturbingly, influential key

members of that advisory group were not required to declare any potential conflicts of interest. Those non-declared interests and funding connections are now well-known to include not only substantial links to the Linbury Trust which had funded some members' own research, but to organisations such as HealthWatch, a pro- pharmaceutical campaigning organisation which lists Simon Wessely as a "leading member" of its campaign and which has accepted money from both the pharmaceutical and medical insurance industries (*ref Hansard, Lords, 28 April 1993:364-382 and Hansard, Lords, 10 May 1995:66-68*) and also to PRISMA, a multi-national healthcare company working with insurance companies to arrange rehabilitation programmes based on cognitive behaviour therapy for those with "medically unexplained symptoms", especially those with "CFS". Of particular note is the fact that Professor Simon Wessely (not only a member of the CMO's Working Group but also advisor to the Centre for Reviews and Dissemination at the University of York which carried out a systematic review of the literature upon whose findings the recommendations of the CMO's Report are based) is listed as a Corporate Officer: he is a member of their Supervisory Board and in order of seniority is above the Board of Management, being listed as a "world expert" in "medically unexplained illnesses, including chronic fatigue syndrome".

Given the way in which the UK ME community has been misled in the past, it may be sensible to start asking pertinent questions, especially if it is the case that Chris Clark from Action for ME has indeed said that he wants psychiatrist Mike Sharpe to be on Action for ME's Research Group. It is the same Mike Sharpe who apparently recommended to insurance companies that claimants with CFS/ME should be subject to covert video surveillance and who, together with Simon Wessely, addressed a symposium on CFS/ME entitled "Occupational Health Issues for Employers" at the London Business School, at which another speaker was Dr John le Cascio, Vice-President of the insurance company UNUM, whose "Chronic Fatigue Syndrome Management Plan" states

- (i) Diagnosis: Neurosis with a new banner
- (ii) UNUM stands to lose millions if we do not act quickly to address this increasing problem
- (iii) attending physicians (must) work with UNUM rehabilitation services in an effort to return the patient/claimant back to maximum functionality *with or without symptoms*

It does not require too strenuous a leap to realise that it may be with AfME's Research Group that the "independent" MRC panel will be discussing the direction of future research into a very serious and complex neuroendocrineimmune disorder, about which the Office of Science and Technology may be only too eager to accept advice from the "independent" and "fresh" MRC panel that "CFS/ME" is, after all, nothing more than chronic "fatigue" and that cognitive behaviour therapy really is the way forwards.

If they are not to lose credibility, how could Linbury Trust members advise otherwise?

On a related issue, since they so frequently suffer from allergies, chemical hypersensitivities and immune dysfunction and therefore need to avoid unnecessary antigenic challenges (*refs: What is Myalgic Encephalomyelitis? AR Lloyd et al, Lancet, June 4 1988:1286; Summary and Perspective: Epidemiology of Chronic Fatigue Syndrome. Paul H Levine. Clin Inf Dis 1994:18:Suppl1: S57-S60*), the ME community may be interested to know a little more about Lord Sainsbury of Turville.

When barely in post, he is known to have had frequent meetings with the chemical company Monsanto only three weeks after he had attended the first meeting of the Cabinet's Ministerial Group on Biotechnology and Genetic Modification known as Misc 6 (see colibri@west.net). David Sainsbury owns two genetic research companies (Diatech and Innotech Investments) and he has given £22.5 million for genetically modified food research through the Gatsby Charitable Foundation. Since he became Minister for Science, David Sainsbury's department has granted the Biotechnology and Biological Research Council additional funding of £50 million. The Chairman of the BBRC, Peter Doyle, is a former executive director of the pharmaceutical company Zeneca.

When in January 2001 the Royal Bank of Scotland announced that it would not extend an overdraft facility of over £22 million to Huntington Life Sciences (Europe's largest vivisection research laboratory situated in Cambridgeshire), Science Minister Lord Sainsbury stepped in to offer Government support. He personally brokered a deal with the American finance house Stevens Inc to save HLS from closure. Current and potential drug company customers of HLS include Zeneca, Eli Lilly, Glaxo Research and Development Ltd and Novartis UK Ltd. Novartis will be well-known to the ME community as the pharmaceutical company which, together with the Linbury Trust, sponsors psychiatrist-driven research into chronic "fatigue".

Huntingdon Life Sciences laboratory was condemned by the UK Home Office in 1997 for cruelty to dogs. The Labour Party holds or used to hold 75,000 shares in HLS despite its pre-election pledge to improve animal welfare and its current Minister for Science is the single most influential promoter of vivisection in Britain. In May 2001 there were reports that the Labour Government had been approaching advertising agencies about launching an advertising campaign to support animal experiments and that it was Science Minister Lord Sainsbury who was behind this. The campaign was intended to convince the public that animal experiments are essential to save human lives but the Department of Trade and Industry found little support for such an advertising campaign, announcing "The decision is not to take it any further at this stage, though this is not an absolute".

There has been a formal complaint about the Minister for Science for breaking the Ministerial Code of Conduct, the essence of the complaint being that the Minister for Science made misleading public statements about animal experiments at a time when the Labour Government was aggressively supporting Huntington Life Sciences.

It is disturbing how easily Government Ministers can mislead the public by circulating misinformation, as the ME and Gulf War communities know to their cost.

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