



Invest in ME

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Chief Medical Officer
The Department of Health
Richmond House
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26 October 2009

Dear Sir Liam,

In 2006 when we corresponded with you in an attempt to make ME a notifiable illness you declined the request. As you wrote in your response to Invest in ME –

“I would like to make it clear, however, that I do not see any prospect of making myalgic encephalomyelitis a notifiable disease. This classification is only used for a small number of infectious diseases where monitoring is clearly required to sources of infection, and not as a means for collecting statistical information on the prevalence of specific conditions.”

Recent research, published in Science magazine 8 October 2009, by the Whittmore-Peterson Institute in Nevada, USA, the Cleveland Clinic and the National Cancer Institute has shown that 67% of ME patients have tested positive for the XMRV retrovirus. In further analysis this figure has risen to 98% of patients tested.

In the light of this research, which indicates that this pathogen may be spread by bodily fluids and is therefore an infectious disease, may we ask you whether you will now reconsider making ME a notifiable illness, not for schools but for the general population?

On 12th May 2009, ME Awareness day, we invited you to “to make the treatment and eventual cure of ME your personal responsibility, something which no other government department or medical research organisation or vested interest can hijack or use for their own purposes”.

As you know Invest in ME organises and hosts an annual International ME/CFS conference in Westminster, London, with the aim of educating healthcare staff, researchers, the media, politicians and patients of the biomedical research which is taking place and of some of the issues with the perception and treatment of ME.

With the news of the XMRV retrovirus being linked to ME we would like to suggest that now would be a good time to refocus efforts on ME and again invite you to make the treatment and eventual cure of ME your personal responsibility.

As part of this process Invest in ME would like to formally invite you to open our 2010 International ME/CFS Conference in London on 24th May 2010.

The conference regularly attracts delegates from many different countries around the world and it would indeed be fitting for the Chief Medical Officer of the UK to open this conference at a time when we may be at a watershed in the perception and treatment of ME.

We thank you in advance for considering our request,

Yours Sincerely,
Kathleen McCall
Chairman Invest in ME