



# *Invest in ME*

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Chief Medical Officer  
The Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS

10 December 2009

Dear Sir Liam,

On 26th October Kathleen McCall, chairman of the UK charity Invest in ME, sent you a letter concerning myalgic encephalomyelitis and the XMRV retrovirus.

The indifferent response received, over one month later, predictably declined our offer to open our biomedical research conference in 2010. Although disappointed we have come to expect that you would avoid agreeing to open our conference yet again.

However, what I find quite shocking is that you completely failed to address the serious question put to you.

I therefore repeat the question to you from Invest in ME, which was this –

**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 Whittemore-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?**

In June 1988 the British government made Variant Creutzfeldt-Jakob a notifiable disease. vCJD is a fatal human neurodegenerative condition, is classified as a Transmissible Spongiform Encephalopathy because of characteristic spongy degeneration of the brain and its ability to be transmitted.

In the light of the new research can you explain why ME would not be seen in the same light?



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In addition to this question, for which we would appreciate an answer, we would also like to ask you why no major comment on policy has been made by yourself on the subject of XMRV.

We believe the CMO should be showing leadership in this issue.

We respectfully await your full reply to these questions,

Yours Sincerely,

Trustee Invest in ME  
Charity Nr 1114035