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O5 January 2010

I refer to your letter of 10th December to Professor Sir Liam Donaldson, Chief Medical Officer, regarding Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) asking that this illness be made a notifiable disease on the basis of recent research findings. Sir Liam has asked me to respond on his behalf.

The research to which you refer is that published in October 2009 in *Science* regarding CFS/ME and the finding of evidence that a new virus, known as XMRV (xenotropic murine leukemia virus – related virus), was present in 67% of CFS/ME patients tested, compared to 3.7% of healthy people tested. Research results also indicated the potential for transmissibility of this virus, following in-vitro cell studies. Though the findings of this research are interesting, they do not support your statement that this research "...indicates that this pathogen may be spread by bodily fluids and is therefore an infectious disease", nor do the findings support a conclusion of a causal role for XMRV in the development of CFS/ME. This is because the research has not demonstrated that XMRV is a pathogen i.e. that it is capable of causing disease, nor has it determined whether or not XMRV is in any way a contributing factor in the development of CFS/ME.

Conversely, the research findings also posed the possibility that those who have already developed CFS/ME may then be more susceptible to harbouring XMRV than healthy people. We need to know far more about the time period over which people test positive for XMRV in relation to the development of CFS/ME in order to understand such potential linkages. Furthermore, you will doubtless be aware of the recently published results from a similar study undertaken by researchers at Imperial College and King's College, London, that showed that XMRV was not present in CFS /ME patients who were tested. As these results conflict with those from the research in the USA, this indicates that far more research is required to establish the answers to these, and other, important and complex questions before any conclusions about the role of XMRV infection in CFS/ME can be drawn.

This research has been brought to the attention of the secretariats for the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) and the National Expert Panel on New and Emerging Infections (NEPNEI),

who will continue to monitor developments in conjunction with the UK Blood Services and the Health Protection Agency.

With regard to making CFS/ME a notifiable disease, I can only reiterate that the prime purpose of the notifications system is to enable rapid control measures to be put in place to minimise the spread of infection and to speed up detection of outbreaks. I must point out that, contrary to your assertions, variant Creutzfeldt-Jakob disease (vCJD) is not a notifiable disease in England. Information on many infectious diseases and non-infectious conditions is collected without the need for statutory notification. Given that there is currently no evidence of an infectious causal agent for CFS/ME, statutory notification is not warranted.

Yours sincerely,

Mrs M L Tomlinson
Infectious Diseases and Blood Policy Branch