Department of Health

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The Chairman
Invest in ME
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By email to: info@investinme.org
Our ref: CMO TO505578 (TO396/2009)

Dear Sir / Madam

Myalgic Encephalomyelitis and Blood Donations

Thank you for your further letter to the Chief Medical Officer (CMO) about chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and blood donations. I have been asked to respond on the CMO's behalf.

There is currently no established cause of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), and a number of different potential aetiologies including neurological, endocrine, immunological, genetic, psychiatric and infectious have been investigated, but the diverse nature of the symptoms can not yet be fully explained. The Department's view is that it is important to recognise that CFS/ME is a genuine and disabling neurological illness and health professionals must recognise it as such.

It is important to emphasise that the National Institute for Health and Clinical Excellence (NICE) clinical guidelines are just that – guidelines for healthcare professionals. The guideline emphasises a collaborative relationship between clinician and patient and recognises there is no one form of treatment to suit every patient but that what is needed is a personalised, holistic approach.

Once NICE guidance is published, health professionals (and the organisations who employ them) are expected to take it fully into account when deciding what treatments to give people. However, NICE guidance does not replace the knowledge and skills of individual health professionals who treat patients; it is still up to them to make decisions about a particular patient in consultation with the patient and/or their guardian or carer when appropriate. Health professionals retain their independence to apply their clinical judgement in deciding which guidelines to use for the diagnosis and treatment of their patients.

As set out in previous correspondence, in the UK, people with diagnosed CFS/ME are excluded from donating blood while they are unwell and have symptoms. This exclusion is purely designed to protect the health of the donor.

UK donor selection guidelines currently state that people who have been previously diagnosed with CFS/ME are able to donate blood once they have recovered and are feeling well. This guideline was recently reviewed by the UK Blood Services Standing Advisory Committee for Transfusion Transmitted Infections. The committee decided that it was premature to make any change to this guideline at this stage, but that the situation would be closely monitored as new evidence became available from the UK and from Europe.

I would like to reassure you that the Department of Health is giving serious consideration to the recent published findings on a gammaretrovirus - xenotropic murine leukemia virus-related virus (XMRV). The National Expert Panel on New and Emerging Infections (NEPNEI) is considering all the available scientific data, and their risk assessment will be used to evaluate any threat to public health.

The Department of Health’s independent Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) will also be considering the findings and NEPNEI's risk assessment and will advise the UK Blood Services accordingly.

I apologise that we were unable to reply in time for your conference on 24 May. I hope you had a successful and helpful conference.

Yours faithfully

Kay Ellis
Blood Safety & Supply Team