

Written by Administrator

Tuesday, 01 March 2011 00:00 - Last Updated Sunday, 20 March 2011 12:15

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**[M.E. and Blood Donations](#) - Letter to Mr. Andy Burnham,  
Secretary of State for Health, UK  
Invest in ME**

**Invest in ME - Letter to UK Secretary of State for Health**

*Recently Mrs Ann Keen, Under-Secretary of State for Health, commented that people with Myalgic Encephalomyelitis were not able to donate blood. Invest in ME have written the following letter to the Secretary of State for Health, Mr Andy Burnham.*

**Letter**

**Myalgic Encephalomyelitis and Blood Donations**

**Rt Hon Andy Burnham MP  
Secretary of State for Health  
Department of Health  
Richmond House  
79 Whitehall  
London SW1A 2NS**

**cc: Mrs Ann Keen MP**

**14th March 2010**

**Dear Mr. Burnham,**

**Recently Mrs Ann Keen (in her capacity as Under-Secretary of State for Health) made the following comments in relation to**

## **Myalgic Encephalomyelitis and blood donations -**

***"People with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), are not able to donate blood until they have fully recovered.***

***The reasons for this are: first, blood donors need to be in good health, and people with ME/CFS often experience a range of symptoms which could be made worse by donating blood; and second, as the causes of ME/CFS are not currently fully understood, people with the condition are deferred from donating blood as a precautionary measure to protect the safety of the blood supply for patients."***

Mrs Keen's comments are, we assume, representative of the government and your department.

Firstly it is good that your government recognises that people with ME are in poor health. This implies that all people with ME are therefore in need of proper healthcare provision which treats the disease properly.

Secondly it is good that you and your government recognise, by the implication from your statement, that blood supplies may be compromised by accepting people with ME as donors due to the organic nature of this disease.

Thirdly it follows that an embargo on people with ME donating blood would mean that there is an infectious agent at work which could be passed on via blood.

**There follows several questions which lead on from this.**

It seems to be crucial to use the most stringent diagnostic criteria available for diagnosing ME (which even NICE acknowledge as being the Canadian Consensus Criteria). Yet your department, NICE and the MRC do not standardise on this internationally accepted standard for diagnosis of ME.

***When you state that people with ME are not able to donate blood are you employing the NICE guidelines for defining patients as having ME?***

***If so then why does NICE proscribe serological testing unless there is an indicative history of infection?***

***If no initial indication of infection is present then no further blood tests are performed and a patient may receive a diagnosis of ME based on ongoing fatigue and one other symptom such as sleep disturbance.***

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***Why then would those patients be excluded from donating blood?***

As your government officially accepts ME as a neurological illness, as described by the World Health Organisation ICD-10 G93.3 code, and as the issue of blood contamination from an infectious agent demands the utmost care and attention, is it not of absolute necessity for your government to demand that a consistent set of up-to-date diagnostic criteria are used as standard by all organisations?

Your department often states that the Medical Research Council is an independent body. Yet as it is apparent that the MRC only funds psychiatric studies which presume that ME is a behavioural illness why does your department refuse to comment on the MRC's usage of the Oxford criteria for research into ME which expressly excludes people with a neurological illness?

Why does your department not criticise the MRC for funding purely psychiatric research into ME if you fully recognise that ME is a disease of organic and infectious nature?

Since when did a psychiatric illness prevent blood donations? Does this not clearly show the MRC policy of research into ME for the last generation to be completely flawed and a waste of precious funding and patients' lives?

***When you state that people with ME are not able to donate until fully recovered please can you define what "fully recovered" means?***

Could you also provide a description of how a person with ME is defined as no longer having ME?

What biomedical tests are available to determine that a person with ME is "fully recovered"?

Could you inform of how and when clinicians perform such tests in order to ensure that a person is "fully recovered" from ME?

Bearing in mind the seriousness of a possible contamination of blood supplies from people with ME please could you indicate what measures are in place to ensure that doctors do enforce testing to ensure that people with ME are "fully recovered" and will not therefore donate blood?

If such a test exists then presumably people with ME who are not recovered are entitled to appropriate benefits due to incapacity and/or disability?

As relapses are common with people with ME please could you explain if there is any minimum period which a person with ME needs to be "recovered" to be able to donate blood?

Could you also provide information which your government has on the number of people with ME in this country, the proportion of patients who have had ME for longer than five years and how many people with ME have \*fully recovered\*?

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With regard to your statement that \*the causes of ME/CFS are not currently fully understood\* is it not inherent on the Chief Medical officer of the UK to attend **the 5th Invest in ME International ME/CFS Conference 2010 on 24th May** in Westminster, as guest of Invest in ME?

As the foremost experts on ME in the world are presenting at the conference, along with the Whittemore-Peterson Institute \*who have recently been involved in the discovery of the XMRV retro-virus which has possibly huge considerations for the blood supply of this country\* would it not be sensible for anyone who is involved in healthcare and particularly in the treatment of people with ME to attend this event?

Should not the government of this country also be sending a representative to the conference given that contamination of the blood supply by people with ME may be occurring and that education about the disease needs to be a pre-requisite for anyone involved in healthcare provision for people with ME?

We would request that you provide a full and complete answer to every single one of the questions which we have asked in this letter and we look forward to your reply,

Yours Sincerely,

The Chairman and Trustees of Invest in ME

Invest in ME  
Registered UK Charity Nr. 1114035  
PO BOX 561, Eastleigh SO50 0GQ

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