



Invest in ME

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

21 November 2009

Subject: Myalgic Encephalomyelitis

Dear Mr. Burnham,

Invest in ME is a UK charity campaigning for appropriate funding for biomedical research into Myalgic Encephalomyelitis (ME) and for appropriate treatments for this illness which is thought to affect 250,000 people in the UK, is the largest cause of long-term absence from school through sickness for teachers and students, and which probably affects directly or indirectly over two million voters in the UK.

In July of this year we requested a meeting with the Prime Minister to discuss the treatment of patients with Myalgic Encephalomyelitis (ME) in the UK. The letter was passed to an official in the Department of Health who provided an underwhelming reply using the same DoH template answers to all of our questions with which we are familiar, and missed many of the points we raised.

On the following page we have provided several questions relating to ME which we are asking of all political parties in the run-up to the election. This will allow the estimated two million or more ME patients and their carers, relatives and friends who will vote in the next election to know where the major parties stand on these issues. We would appreciate if we could obtain the government's position on these issues.

However, to avoid a repeat of the reaction to the letter to the PM we would also like to organise a representation from the ME community to meet with you personally and discuss why we feel your government is not doing enough to resolve the continual problems which people with ME and their families encounter.

In light of the recent research into ME performed by the Whittemore-Peterson Institute of Nevada, the US National Cancer Institute and the US Cleveland Clinic, in which a retrovirus was found to be present in a majority of ME patients tested, we believe that ME should be made a notifiable illness and a major programme of biomedical research should now be undertaken, something which the Medical Research Council (a supposedly independent body) should have performed over the last decade. We have previously invited the Chief Medical Officer to consider making ME a notifiable illness as the recent findings from the WPI research make the potential implications of this illness to the general public as serious as the H1N1 flu virus.

We propose that we visit you at your early convenience, during which we can try and arrange a link up to the Whittemore-Peterson Institute in Nevada so that you may discuss the implications for the general population of this discovery of XMRV with the researchers who discovered this.

We look forward to hearing from you,



Invest in ME

Yours Sincerely,

Kathleen McCall
Chairman Invest in ME

Questions to the Labour Party Regarding Myalgic Encephalomyelitis

We would like to ask the Labour party to respond to these seven questions -

1. In the light of the recent XMRV research findings will you support calls to ensure that the Department of Health allocates adequate, ring-fenced funding for dedicated biomedical research into ME which uses cohorts diagnosed according to the Canadian Consensus Document?
2. Will you support calls to make ME a notifiable illness now that the recent XMRV research has indicated ME is an infectious disease?
3. Will you support Invest in ME in its request to modify the training curriculum for all doctors and nurses to ensure that they have an adequate understanding of the physiology of ME, knowledge of the Canadian Guidelines for diagnosing ME and knowledge of the latest biomedical research into ME?
4. Will you encourage GPs to specialise in ME and apprise themselves of the latest biomedical research and possible treatments available?
5. Will you support Invest in ME in its attempts to set up a national centre of excellence for ME which will perform translational research into ME as an organic illness and provide treatments for all ME patients from the severe to the mildly affected?
6. Will you support Invest in ME in its attempts for ambulatory services to be made available for all severely affected people with ME which would allow visits by ME specialists to the homes of those who are unable to visit hospitals or GPs?
7. Will you encourage the Department of Work and Pensions to adequately train their assessors in the physiology of ME as a chronic neurological illness and provide disability forms which have questions which truly reflect the nature of this illness?