



INVEST in ME

The Rt. Hon Gordon Brown MP
10 Downing Street
London SW1A 2AA
United Kingdom

6 July 2009

Subject: E-petition response

Dear Mr. Brown,

In March of this year an e-petition was raised (<http://petitions.number10.gov.uk/AttendIiME2009/#detail>) asking the "Minister of Health, Medical Research Council delegates and the Chief Medical Officer to attend the INVEST in ME Conference 29th May 2009 London". The petition was raised in March 2009 to allow enough time for the question to be raised to the relevant parties before the conference date of 29th May 2009.

On 1st July 2009 (over three months after the petition was raised and two months after the petition was closed) your office replied (<http://www.number10.gov.uk/Page19853>).

Invest in ME are profoundly disappointed by the continuing indifference to ME which the perfunctory response from your office has shown – and yet we hoped that perhaps we could expect more from our Prime Minister.

The petition was a genuine attempt to engage your government and the organizations/officials which you fund with public money. It was an endeavour to provoke some understanding of the issues involved in the current policies toward ME research. By attending the foremost biomedical research conference on ME in Europe your officials would be better equipped to understand the possibilities and the potential available in treating this debilitating illness.

The reply from your office is insulting in its complete lack of engagement of the proposal and of the underlying issues associated with this request.

It gives no joy for us to pronounce that your government is failing a large section of the UK population – people who are chronically ill and who are hoping for leadership and vision from the person who has the power to change things for the better. Your office states that

"Ministers and the Chief Medical Officer receive a large number of invitations from stakeholders, pressure groups and individuals to attend meetings and events" and "it is not possible to attend the vast majority of these events".

This was Invest in ME's fourth annual international conference held in Westminster. We have been asking for the government and the CMO to attend in each of the last four years. The Department of Health has not sent one representative in all of that time.

Your office states that "The Medical Research Council is an independent organisation and it would therefore not be appropriate for the Prime Minister to instruct it."



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The MRC is a publicly-funded organisation “dedicated to improving human health”. It should be accountable to the public. The MRC receives annual ‘grant-in-aid’ funding from Parliament through the Department for Innovation, Universities and Skills and its council members are appointed by the Secretary of State for Science and Innovation.

It is entirely appropriate for the Prime Minister to intervene when there is deliberate bias being operated by this “independent” body which is, nevertheless, supposedly accountable to a government department.

The MRC has provided a total investment of £3,180,900 in funding research projects concerning ME – this money going to psychiatric therapies such as the PACE and FINE trials. Both of these trials are considered meaningless by ME patients and are ridiculed for their lack of scientific rigour in identifying true ME patients. Even those who have participated have criticised these trials. Your government officially recognizes ME as a neurological illness, as does the World Health Organization, yet you allow this “independent” body to avoid funding any biomedical research into ME and instead it supports vested interests who instead use this funding to pursue their own agenda of research into their own chosen fields of psychiatry. The latest ploy by the MRC of creating a panel intent on tying both biomedical and psychosocial factions together will be a liability for future research into ME and we have no faith or belief in their seriousness in looking for appropriate treatments for this illness.

It is a scandal that the MRC causes the prolongation of such an appalling waste of life and scarce resources; that it seems to lack any accountability for its actions (or lack of action); that it does not serve the patient community; that it is systemically flawed with a refereeing system for research proposals that is neither transparent nor fair; and that it ignores requests to attend a conference providing the latest information on biomedical research which is being held on its doorstep and which could lead to improvement in human health.

We cannot comprehend why you and your ministers feel it “inappropriate” to intervene to understand why the MRC policy toward research into ME is a failure.

The crass referral to the UK Clinical Research Network of the National Institute for Health web page in your reply to the petition indicates that there is nobody in your office who really understands anything about ME. We found just two references on that site regarding research for ME (the PACE Trial and the FINE Trial) - using the term chronic fatigue or chronic fatigue syndrome rather than myalgic encephalomyelitis.

The one-size fits all approach of your government, of NICE and of the MRC in supporting only Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) for people with ME – therapies rejected by the ME community – is testament to the lack of ideas and the lack of commitment by your government. We know of no patient groups who welcome studies into CBT and GET apart from two organisations who accept money from your government to support your policies.

NICE was taken to judicial review by ME patients due to their unsatisfactory guidelines for ME. Yet your government does nothing to recognize the dissatisfaction with your and their policies.



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Your reply states that –

“some recent findings about a genetic basis of CFS/ME that are providing extremely valuable insights into the causes of, and possible therapies for, the condition these are early research findings that at present have no direct relevance to any predictive or diagnostic gene test for these conditions. However, the Department of Health continues to keep such developments under review and there are well-established mechanisms to evaluate new genetic findings and ensure their proper implementation across the NHS.”

This is a pitiful response which is condemnable by its lack of up-to-date information and patent spin. It is symptomatic of a government which doesn't understand, doesn't bother to verify, and cannot be bothered to do anything.

Your “independent” MRC refused to fund world-class research from Dr Jonathan Kerr which is clearly seen by others abroad to be state of the art. Why is public funding for this valuable gene research being constantly refused? It has been funded entirely by small charities and many individuals donate from their benefits because they are so desperate for proper treatments being developed instead of being offered only CBT and/or GET.

If any of your government ministers or officials had bothered to find the time to walk a few hundred metres to the conference venue on 29th May this year then they would have been able to judge for themselves how fatuous the response from your office is.

There is substantial evidence now of effective treatments for some sub-groups of ME. Antivirals are one example yet no funding has been made available for performing clinical trials and PCTs do not allow patients to be given these drugs. Yet how hypocritical the situation is when your Chief Medical Officer allows antivirals to be made freely available to any person suspected of contracting swine flu despite fewer people suffering from this flu variant than ME.

ME is the largest cause of long term absence from school through sickness for pupils and staff yet your CMO refuses to make ME a notifiable illness in schools. Yet one case of swine flu frequently closes a whole school for weeks!

The DoH is not reviewing the treatments which are available for ME. The CMO is not recommending research trials be carried out on promising treatments which privately funded research has identified. Even the most basic and obvious action which should be required – an epidemiological study of ME in the UK – has not been performed by your government.

The use of a current and sound set of clinical guidelines for ME has not yet been standardized. The Canadian Guidelines document – held by most ME advocates as the best of the guidelines for diagnosis – is not advocated yet by the NHS or DoH despite it now becoming the de facto standard across the world.

Quite simply your government's policy towards ME is non-existent and its attitude toward people with ME and their families is nothing short of scandalous.

Invest in ME has, in its four years of existence, attempted to educate healthcare staff, the media and the public about the real situation with ME, and show the



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biomedical research which is being carried out and which holds the promise of effective treatments and cures. Consistently your government has refused to acknowledge any of this.

And yet how easy it would be to change this with a clearly defined strategy of biomedical research which could be funded by public and private funding, if there was a will to do so.

Invest in ME began distribution of the book "Lost Voices from a Hidden Illness" earlier this year. Once delivery began we took the liberty of sending a complimentary copy to your wife, Sarah, who is global patron of the White Ribbon Alliance for Safe Motherhood and co-chair of the High-Level Leadership Group on Maternal Mortality convened by the Global Leadership Network.

ME is more prevalent in women, affecting up to four times as many women as men according to some studies. Many women with ME will never be mothers as they have fallen ill as teenagers and spend decades being bedbound. Many mothers have to watch their children's suffering for years on end without any help from the health services.

Lost Voices is probably the best book ever about ME which shows the true picture of the effect of ME on sufferers and families.

We have received neither acknowledgment of receipt of the book nor any indication that the book has been read.

If only one of your ministers would read Lost Voices then there would be no need for any further debate. The very basic compassionate instinct of most human beings would demand immediate action.

Your government fails its citizens, refuses to take any action, ignores the effort of two and a half thousand people who petition you to help them, looks the other way to the plight of the hundreds thousands of citizens affected by this terrible neurological illness and concentrates on spin and ignorance as the cornerstone of your policy toward ME.

A year ago you gave a speech in which you stated that -

"The NHS of the future will do more than just provide the best technologies to cure: it will also - as our population ages and long-term conditions become more prevalent - be an NHS that emphasises care too."

"It will not be the NHS of the passive patient - the NHS of the future will be one of patient power, patients engaged and taking greater control over their own health and their healthcare too."

"With cutting-edge techniques from genetics to stem cell therapy - and life-saving drugs to prevent, alleviate or cure conditions"

"So if we are to prevent as much suffering and save as many lives as possible, it is clear that utilising these new technologies must continue to be at the heart of any progressive health policy."



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In the last year Invest in ME are aware of people dying from ME, as has happened over the last decades.

We are aware of a family where the mother suffered from ME and where the pain was so great that she was taken to Switzerland to perform an assisted suicide.

We know of a recent case of one mother who has been charged with assisting her daughter in taking her life after she had suffered from severe ME for almost two decades – the pain being unbearable to endure.

We know of patients in the heart of London who suffer for years from ME and receive absolutely no medical treatment – lost voices with no recourse to help from a government and a healthcare service which provide nothing.

We know only too well of children who lose their teenage years and become isolated and reduced to utter dependency on parents who themselves struggle to find any help from the NHS, from the educational establishment or from ministers.

It is easier for people in the UK with ME to get help to die than it is for them to get help to live – thanks to your government's policies.

Your government's health ministers have consistently avoided taking any action, continued to answer the petitions and letters from people with ME and their families by using outdated information, template paragraphs containing multiple inaccuracies and an indifference to the plight of chronically ill people.

The cursory response to a valid plea from people with ME and their families shames your government and gives the lie to the sentiment that you really care for what happens to citizens in this country.

In this letter to you we have only concentrated on healthcare provision. We have not even begun to mention the effect of the policies of your government which force chronically ill people with ME to be denied benefits or to spend all their energy on battling to regain benefits taken away by your government departments.

So what are ME patients and their families to do now having received this appalling response from your office?

Despite no epidemiological study being recommended by your government or insisted upon by the health service we can suspect, from studies performed by responsible researchers, that there are between 120,000 and 240,000 people affected by ME in the UK.

Many of these can be expected to have some family and these, in turn, can be expected to have immediate friends and relatives.

It would be no exaggeration to assume, then, that upwards of two million people will be directly affected by the lack of healthcare provision for people with ME – either as direct sufferers of the illness, direct relations or friends of those affected. This figure could be a very conservative figure.

Although Invest in ME does not hold party political views it is an obvious corollary that two million citizens, or more, make up a substantial number of voters who cannot be ignored and who may decide with their votes what they think of the Labour governments' policies toward ME over the last decade.



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It may be that ME organizations can mobilize enough of a protest to make a difference in the forthcoming election and that would, indeed, provide an irony where, to use your own words, the “future will be one of patient power”.

Before we contemplate that action we would ask that you yourself make an hour or two of your time available and devote it to the cause of people with ME.

We ask you to accept a party of individuals organized by Invest in ME to visit you and explain clearly what is required and how your government’s lack of action is destroying lives – or let us take you to a chronically ill patient with ME so you yourself can see the utterly appalling situation which exists for people in this country who are denied treatments (which exist) due to the ignorance of the healthcare service, government ministers and establishment organizations responsible for deciding on which research is given funding.

Letters, petitions, emails and the deaths of people with ME have not moved your government to act.

Will you now see the desperate need for action, meet with us and let us try one last time to make you understand what is really happening?

Show us that, as Prime Minister, you and your government have not abandoned basic ideals of justice and humanity being directed towards its own citizens.

Time is passing not just for your government – more importantly it is also passing for another generation of sufferers from this illness.

Yours Sincerely,

The Chairman and Trustees
Invest in ME
Registered UK Charity Nr. 1114035
www.investinme.org