



# Invest in ME

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Rt Hon Jeremy Hunt MP  
Secretary of State for Health

## **Request for Secretary of State for Health to Participate in Webinar with ME Patients**

Dear Mr. Hunt,

Invest in ME is a UK charity which seeks to improve education about and awareness of Myalgic Encephalomyelitis (ME). The charity also attempts to facilitate research and funding to establish an understanding of the aetiology, pathogenesis and epidemiology of ME. Invest in ME are founder members of the European ME Alliance, a group of 11 European national patient organisations campaigning for ME awareness and research in Europe.

We believe that a major review of the way that ME is dealt with by the NHS needs to be made. The current limited research and treatment options are poor and most patients are often left with no medical attention. There is a lack of a regular or specialist treatment option available for people with ME. In addition healthcare staff are often quite ignorant about the disease and have little knowledge of the current state of biomedical research into the illness. The damage being done to ME patients in UK is clearly evident to our charity – primarily because the healthcare service treats the disease as a somatoform illness, despite the official UK government recognition of ME as a chronic neurological disease.

This then gives rise to misdiagnosis and maltreatment.

The statistics around ME seem to be shocking (with suicides due to the severity of the disease and the lack of hope for treating it, the terrible plight of the severely affected, the minimal amount of attention given to an acknowledged chronic disease, the deaths of young people due to the effects of ME). This disease is treated so differently from other long term conditions, without anyone seemingly able to explain why – although we feel we know the reasons why?

Considering the estimated number of people with ME (over twice the number for HIV or MS) this is a terrible indictment on the current state of healthcare provision for people with ME.

Rather than just complain, however, we wish to do something about it.

With the change of government and health minister there exists a unique opportunity to change course and establish a new way forward which can lead to appropriate research and treatments for people with ME. We hope that you will be able to help in this and become the first minister of health who would actually champion the cause for people with ME and their families.

We have suggested a simple but effective structure for providing services and instituting major biomedical research into this disease which could have profound effects on the way ME is treated in the UK and could establish a hub of scientific and clinical excellence for ME within Europe. We plan on funding and facilitating high-quality biomedical research into ME and allow for consultant expert examinations for patients in the region which would allow a translational biomedical research environment to be created and which will change patients' lives and begin the work to uncover the causes and possible treatments for this awful disease.



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Allied to this proposed facility we are working with commissioning groups to set up a trial of the use of telemedicine for ME patients which would allow clinical expertise and research opportunities to ME patients.

Of course, we welcome your support for this initiative which is an excellent example of the Prime Minister's 'Big Society' in action (the PM has already facilitated a meeting with the NHS Commissioning Services after a visit from a constituent).

However, we feel that it is imperative that the health minister is personally aware of the problems that people with ME encounter.

## **Our Request**

We would therefore like to ask you to participate in a webinar about ME– organised by Invest in ME and taking place in Westminster at a date that is convenient to you.

We shall organise experts on ME to be present.

We will facilitate an open, live session which would allow all patients and carers around the country, via the internet, to participate and pose questions to you.

This would allow many patients to have a voice and would allow you directly to hear of the issues which people with ME face on a daily basis.

Subjects which clearly need to be discussed are the lack of usage of correct, up to date guidelines for diagnosing ME which confuses and invalidates diagnosis and research into the disease; the failure of NICE to protect patients with ME; the lack of an up to date epidemiological study which we have proposed to the CMO previously; why the NHS does not see ME as a clinical priority; the lack of proper training of medical professionals with regard to ME, the lack of consultants who are knowledgeable about the latest biomedical research into ME and to whom patients may be referred.

However, rather than just go over what has been wrong or missing in the past, we wish to look for solutions for the future.

With the help of the ME community and your support we can together change the future for a large section of the population who have, for too long, been stigmatised and forgotten. The webinar will be an opportune event to allow a sea-change to be made in the way that people with ME are treated. We would also invite the Chief Medical Officers in the UK also to participate.

From this we could perhaps build a regular event – something which would only contribute to better understanding and more hope about this disease.

The charity is also organising its 8th annual International ME conference in Westminster on 31<sup>st</sup> May 2013 – an event which regularly attracts delegates and speakers from 20 different countries – and with researchers, healthcare staff ME support groups, patients and media representatives attending.

Around this time we will be organising other events and we would welcome the chance to bring researchers to discuss with you in Westminster. You are, of course, invited and welcome to attend the conference on 31<sup>st</sup> May – and we would welcome your involvement in the proceedings.

Many thanks in advance for considering our request,

Yours sincerely,

The Chairman and Trustees of Invest In ME