



Charity number 1153730

Invest in

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PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

Tel: 02380 643736 07759 349743

email: info@investinme.org web: www.investinme.org

Sir Simon Stevens
Chief Executive
NHS England

By email: england.ce@nhs.net

Myalgic Encephalomyelitis (ME)

13 February 2017

Dear Sir Simon,

Invest in ME Research is a UK charity (charity nr 1153730) that aims to educate and campaign for research and funding of the neurological illness myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Invest in ME Research are founder members and current chair of the European ME Alliance, a group of 13 European national patient organisations campaigning for ME/CFS awareness and research in Europe.

A group organised by the charity (researchers, academics, patient advocates) recently met the **Deputy Chief Medical Officer, Dr Gina Radford**, to discuss the situation with ME/CFS in England and UK.

Dr Radford suggested it would be advisable to meet with the head of the NHS as some issues were outside of the CMO's remit. We would like to enquire whether you would be willing to meet with our group in London to discuss the issues and treatment of ME. The date can be one of your choosing.

This meeting would be a wonderful way to make progress in understanding and treatment of this disease and make everyone aware of the biomedical research that the charity is funding and the possibilities with the approach we are taking which will benefit all patients with ME and reduce the burden on healthcare services and budgets in the future.

The NHS is currently wasting a huge amount of funds in giving failed therapies to ME patients which are either useless, or deleterious to the health of ME patients.

More importantly these therapies are rejected by patients and, at a time where the NHS needs all the funding it can get, there is no sense in wasting resources or funds like this.

We need to do things differently.



We have previously discussed the situation with Dr Martin McShane (NHS Commissioning Board Authority, Director - Domain 2- Improving the quality of life for people with Long Term Conditions) – but nothing of any value came from that meeting.

The charity is currently funding and facilitating biomedical research into ME/CFS at UCL in London and UEA/IFR in Norwich – with links to other universities in Europe and USA.

The charity is making good progress in building a foundation of research into ME – here in UK and internationally.

We do feel it would be worthwhile to inform you of this and discuss with you ways we feel improvements could be made for the benefit of people with ME, and their families.

The charity continues its efforts to establish a UK Centre of Excellence for ME in the Norwich Research Park and have facilitated the establishment of a European ME Research Group (EMERG), which is chaired by Professor Simon Carding, Head, Gut Health and Food Safety Research Programme at the Institute of Food Research (IFR).

The charity organises an annual CPD accredited Research Colloquium in London (31st May – 1st June) and an International ME Conference (2nd June) – our 7th annual Colloquium and 12th annual conference - and delegates attending from almost twenty countries. You are very welcome to attend these events as our guest.

Thank you in advance for your consideration of our request,

Yours Sincerely,

/Invest in ME Research