



November 2016 Newsletter

Welcome to the November 2016 newsletter.

Invest in ME Research to Meet CMO of England

Here is a short news item from Invest in ME Research concerning the perception and treatment of ME in UK.

Recently Invest in ME again invited the Chief Medical Officer of England to our International ME Conference on 2nd June 2017 in London [1].

Regrettably this invitation was declined.

However, after the recent orchestrated, biased and misleading headlines relating to the PACE Trial II on children - encouraged by the Science Media Centre and establishment media organisations such as the BBC [2] - then we feel a new approach is required.

In England, the CMO is a member of the board of the National Health Service (NHS), a civil servant in the Department of Health, and head of the medical civil service. So this presents us with an opportunity to cover failings in these areas.

We must change the false view of ME constantly being represented by some charities and the media.

The CMO has a duty to be informed - and support good research and clinical practice.

We have therefore arranged a meeting with the CMO in London which will include our advisors and cover areas such as policy around ME since the last CMO report [3], epidemiology of ME, current/future international research, education regarding ME etc.

Invest in ME Research is already approaching the issues around ME with an international context.

We have already engaged with researchers and clinicians in other countries. So in this discussion we can also use the knowledge and collaborative activities from discussions the charity has had with all of our international contacts.

Along with our colleagues in the [European ME Alliance](#) (EMEA) we are looking at ME in Europe and EMEA has been working very hard within the European Federation of Neurological Alliances (EFNA). We will have news of developments here very soon.

We are also in continuing discussions with NIH on ways to improve diagnosis, research and treatments for ME.

Regarding the CMO meeting - this is a UK problem -and therefore requires a UK strategy.

Invest in ME Research has therefore invited the CMOs of Scotland, Northern Ireland and Wales to this meeting.

We do not know if the invitations will be taken up.

But a *Summit of CMOs for ME* - that sounds like something that could be useful.

All of the UK's CMOs have been invited to our [12th International ME Conference 2017](#) in London



We are constantly guided by our driving principal - this issue is urgent.

As we stated in our response to the IOM report [4] -

"This problem needs to be fixed so the clear message from IiME to NIH and IOM is - FIX IT!"

The same applies equally to the UK.

People with ME and their families and carers deserve better.

They also deserve action.

References:

[1 IIMEC12 12th International ME Conference](#)

[2 BBC Reporting of FITNET-NHS trial](#)

[3 CMO Report 2002](#)

[4 INVEST IN ME RESPONSE TO INSTITUTE OF MEDICINE DOCUMENT "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness"](#)

This news item is at this link - <http://www.investinme.org/IIME-Newslet-1611-01.htm>

***"Things don't have to be the way they are -
we can change things"***

- Dr Ian Gibson

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