



# *Invest in ME*

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## **Invest in ME's submission to the APPG for ME on 17 March 2016**

### **2. CLOSE TO COLLAPSE – SOCIAL CARE INQUIRY**

This may look like an admirable task to set out but we find it does not address the reasons for lack of social care for ME patients.

The Close to Collapse reports states:

“misunderstanding, misinformation and stigma surrounding the label of M.E./CFS acted as a deterrent to asking for help for 38% of respondents and was also perceived to impact on the fairness of assessments and the type of support provided”

Yet we already know this!

But from where does this misinformation and stigma originate?  
Why is this still happening despite the CMO Report of 2002?

We would suggest it is the result of years of funding of the wrong research that tries to justify the use of CBT and GET as primary treatments for people with ME.

The PACE trial, which cost £5 million of tax payers' money, was able to go ahead with support from Action for ME and it has shown to be a **total disaster**.

Unfortunately, people with ME have had to suffer the consequence of the policies put in place based on the faulty NICE guidelines - and then the flawed PACE trial claiming that ME patients can get 'back to normal' with CBT and/or GET.

It is 10 years since former MP Dr Ian Gibson took it upon himself to take action and formed an Inquiry into ME. From all of his recommended actions, some of which still today would make a vast improvement if acted upon, nothing has happened.

Most of the problems in this report could be avoided if ME was genuinely treated as a physical illness by all involved in the care of the patients. Yet the healthcare system in this country is still heavily biased to treating ME as a behavioural illness – thanks to a decade or more of influential psychiatrists and others deciding MRC and government policies.

It is also hypocritical of the APPG to suggest an inquiry into lack of social care at a time when many MPs, including some involved in the APPG group and some patrons of some of the charities being represented at this APPG, have just voted in favour of benefit cuts affecting those on low incomes including a large number of people with ME. The government budget is suggesting cuts to adult social care as well.

One of the biggest challenges for ME patients that Invest in ME have found is the effects of applying for, and being denied benefits, due to the poorly conducted and poorly qualified assessments which are carried out for this government by corporate parasites who have government targets to avoid benefits being paid.

These assessments and any subsequent appeals (which are now being penalised as well by this government) cause so much distress to ME patients and their families that the biggest improvement to the welfare of these patients would be to remove these scandalous and inaccurate procedures.

This is now going to be compounded by the planned reductions in benefits being forced on these disabled patients then ME patients can look to further hardship.

How is this compatible with this proposed inquiry and how can this group claim to be attempting to make things easier and better for ME patients?

Actions speak louder than words.

Yet all we see from this report and from this group is more talking, more delay, more of the same.

Instead why not tackle the real causes of the stigma, the poor services, the lack of respect and dignity given to people with ME?

What we would prefer is this –

How many ME patients are there in the UK? Nobody knows. Yet the NHS could acquire this from existing sources. Why not investigate this?

Let us see the real cost to the nation of leaving a section of the population to fend for themselves.

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If we assume the figure is from the recent HoC written answer (270,000) then why does the CMO not make this a target for her to do something? So an inquiry into the DoH treatment of ME and their attention to ME should be performed.

This assumption compares with HIV/AIDS (103,000) [1], MULTIPLE SCLEROSIS (100,000) [2] and Dementia (850,000) [3].

By these figures it would seem imperative that the CMO take action. Yet every single invitation to the annual International ME Conferences organised in London by Invest in ME has been declined by the CMO.

The NICE Guidelines were so poor that patients themselves took NICE to a Judicial Review to oppose them. Now NICE refuses to look at these guidelines for ME again and have placed them on the static list. Why? Inquire that!

Asking for more advocacy only serves to cover the real problems. The benefits available and services that all patients deserve should be applied to all disabled people so why should ME be different? Everyone is entitled to that information.

We are absolutely appalled with the apathy of successive governments and the complete lack of intent by health secretaries and the Department of Health to tackle the real cause of all of these problems.

More talking is not what we need – try action instead and make people accountable!

## **5. RESEARCH UPDATE**

Invest in ME's funded research continues with the UK gut microbiome project ongoing at UEA/IFR – and with more PhDs being recruited to continue research.

Invest in ME funded research on B cells has just been published in Clinical & Experimental Immunology and this work continues. It is being done in collaboration with researchers in Bergen, Norway where rituximab has been trialled and continues to be trialled as a treatment for ME patients.

Invest in ME initiated and arranged for the European ME Research Group (EMERG) to be formed - a group of European researchers collaborating and sharing knowledge.



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EMERG will meet again in London at the Invest in ME conference arrangements for 2016 – BRMEC6 – the 6<sup>th</sup> Biomedical Research into ME Colloquium on 1-2 June and the 11<sup>th</sup> International ME Conference on 3<sup>rd</sup> June.

Yours Sincerely,

Kathleen McCall (Chairman) and Trustees of Invest in ME

## References:

- 1 <http://www.tht.org.uk/our-charity/Facts-and-statistics-about-HIV/HIV-in-the-UK>
- 2 <https://www.mstrust.org.uk/understanding-ms/what-ms/introduction-ms?gclid=CLPJ9Yb7tcsCFdMV0wod8BwN5A>
- 3 <https://www.alzheimers.org.uk/statistics>