Invest in ME Research

The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK

1.About IiMER

Invest in ME Research is a UK charity which seeks to educate about Myalgic Encephalomyelitis (ME or ME/CFS). Founded by ME patients and parents of children with ME/CFS the charity aims to campaign for research and funding to establish an understanding of the aetiology, pathogenesis and epidemiology of ME. Invest in ME Research is a founder member, and current chair of the European ME Alliance, a group of 15 European national patient organisations campaigning for ME/CFS awareness and research in Europe.

The charity has so far organised fourteen annual international CPD-accredited ME conferences in London that have attracted delegates from 20 different countries. The charity has also organised nine international research colloquiums bringing researchers from around the world to London to build collaboration and sharing of knowledge.

The charity has campaigned consistently for a strategy of biomedical research into ME.

2.Centre of Excellence for ME

What is required is a model which has been described by Invest in ME Research since 2010 which involves concentrating research into a hub with translational biomedical research and appropriate examinations of patients, correct diagnosis, biomedical research and development of efficacious treatments.
Status document is available – **click here**

A parliamentary debate is to be held on 24th January 2019.

We call for

- **A Public Inquiry into ME**
- **Implement the Revised CMO Report Recommendations**
- **Removal of Existing NICE Guidelines for ME immediately**

- **Annual Report to Parliament of the Status of ME**
- **Transparency of Meetings Concerning ME by MRC**
- **Removal of Those Previously Responsible for ME from Positions of Influence**
- **Research Funding**
- **Guidelines for diagnosis must be as accurate as possible and must be up to date.**
- **The CMOs of UK Must Annually Report on Prevalence of ME in UK**
- **Patients Diagnosed with ME Need a Regular Follow-up pathway**
- **NICE Must Follow Department of Health View of ME**
- **A specialism consultant needs to be established for ME**
- **Medical curricula need to be revised.**
- **Education needs to extend to social care.**
- **Schools need to be educated about ME.**

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