Invest in ME Research
NEWSLETTER

November 2016 Newsletter II

Welcome to the second November 2016 newsletter.

Friendly Fire?

As a charity set up and run by volunteers then it might be expected that other ME charities would be supportive of Invest in ME Research's attempts to build a strategy of biomedical research into ME, in the best interests of patients suffering from this disease and their families.

So it comes as a surprise that, in recent days, Invest in ME Research has been made aware of an approach to our advisory board from Professor Stephen Holgate (chair of the CFS/M.E. Research Collaboration (CMRC)), at the suggestion of a trustee of another charity and CMRC board member.

All of this without the knowledge of Invest in ME Research.

When we were included in the reply by our advisor to Professor Holgate, which showed the emails in full, it did appear to be an attempt to influence the affairs of Invest in ME Research.

We have, therefore, sought clarification directly from Professor Holgate regarding these emails and the position of the CMRC with regard to this.

The matter of a trustee of another charity suggesting to Holgate that he approach our advisors without our knowledge is a matter for the trustees in that other charity - and perhaps their members.
A week on from this sorry affair and we have received no reply from Professor Holgate to our letter to him.

Perhaps Sir John Savill, CEO of MRC, may respond in his place - we sent the letter to him also.

Welcome to the *Fog of ME Politics* - read more here.

Read comments from one of Invest in ME Research's advisors who was contacted in this way click here.

Opposing MEGA - The Patients Voice

The above was, of course, precipitated by patients setting up a counter petition to oppose the planned MEGA (M.E./CFS Epidemiology and Genomics Alliance) proposal - formed by the CMRC - which Invest in ME Research has declined to join and which includes some who were responsible for, or heavily supported the PACE Trial.

The counter petition **OMEGA - Opposing MEGA** - has now surpassed the numbers of the MEGA petition during a shorter period of time - an incredible achievement considering that the patients organising the OMEGA counter petition did not have the support of the establishment and establishment organisations behind them.

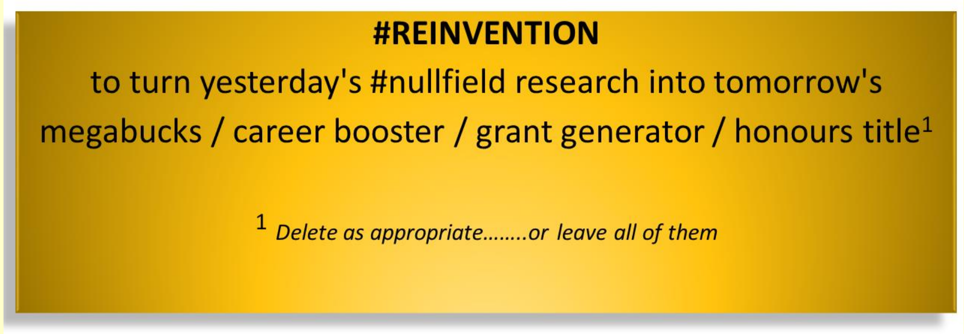
There is nothing in the recent week's events which would lead us to change our views - click here.

Reinvention - The Cycle of Research into ME in the UK

The latest extensive and biased media coverage given to the biopsychosocial (BPS) lobby has been prominent, not for providing anything new – it is always all the same.

What is new is the way that these protagonists for the BPS lobby, and their supporters, are now beginning to sprinkle their language with 'biological' and 'biomedical' – and attempting to morph into something more acceptable to ME patients who have criticised the dead-end approach of UK research in the last generation.

This REINVENTION doesn’t fool anyone but the most naïve.



#REINVENTION

to turn yesterday's #nullfield research into tomorrow's megabucks / career booster / grant generator / honours title[1]

[1] *Delete as appropriate……..or leave all of them*

[Read more](#)

However, despite the above distractions we can state that we will not be diverted by political games by others who do not share our objectives or misinformation in the media.

So let us now return to the good news and items which will take us forward in researching and treating ME.

BUILDING A FOUNDATION FOR BIOMEDICAL RESEARCH INTO ME

www.cofeforme.eu

Centre of Excellence for ME

COLLABORATION BETWEEN HAUKELAND AND UK CENTRES

We are pleased to announce that Dr Oystein Fluge and his team from Haukeland University Hospital in Bergen, Norway, will be visiting the Norwich Centre to continue and extend the collaboration between IiME-funded researchers as the plans for the UK rituximab trial develop.

Our strategy is also founded on international collaboration - of the right stuff. This development is a further example of that strategy taking effect.

Read more

UK CENTRE OF EXCELLENCE FUNDING NEWS

Landmark Day for Research Funding

We have reached a landmark day in our B-cell/rituximab research project where the total in donations and pledges has reached £1/2 million.

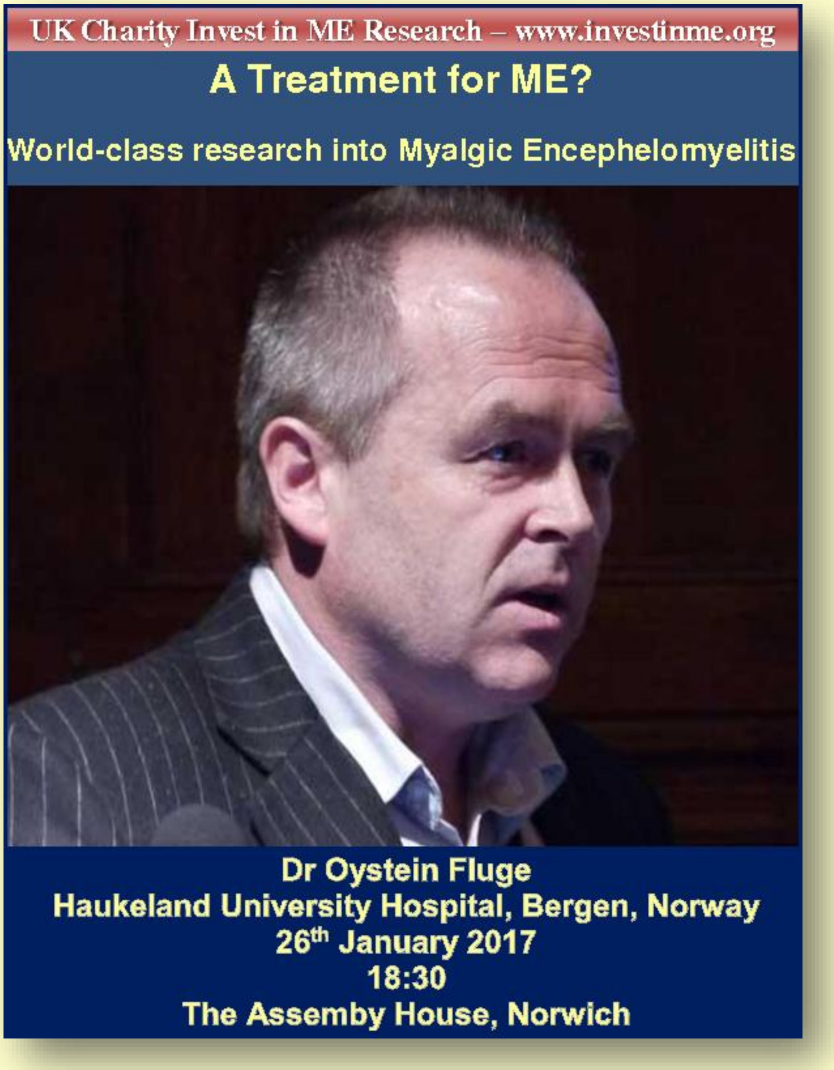
Our supporters have achieved an incredible feat in making something out of nothing and creating an opportunity for real progress to be attained for ME research.

This total includes funds already released for the preliminary B-cell study and the continuing B-cell research being undertaken at UCL.

But with the excellent collaboration formed already with UK researchers and those in Europe then the Invest in ME Research strategy is really gaining ground.

Read more

Dr Øystein Fluge to Give Public Talk in Norwich



UK Charity Invest in ME Research – www.investinme.org

A Treatment for ME?

World-class research into Myalgic Encephelomyelitis

Dr Oystein Fluge
Haukeland University Hospital, Bergen, Norway
26th January 2017
18:30
The Assemby House, Norwich

We are pleased to announce that Dr Øystein Fluge and his team from Haukeland University Hospital in Bergen, Norway, will be giving a public lecture in Norwich on 26th January 2017.

This will be a wonderful opportunity for researchers, doctors, medical students, patient groups, patients, carers, the media and the public to become informed of the current research being performed and the trends in future research from one of the best ME research teams in the world.

The event will also kick off the UK Centre of Excellence campaign to raise more awareness of the unique possibilities with the of the international research centre.

Please contact Invest in ME Research if you are interested in attending this event - bookings are necessary for what we anticipate will be a very popular event.

Read more

Please Support Us

The UK Centre of Excellence has five PhDs working on ME.

Please support our Big Give appeal - click here

or help us raise awareness of the UK C of E for ME by using our poster below

#CofEforME **#letsCresearch**

COLLOQUIUM/CONFERENCE NEWS 2017

We hope to include another Student Q&A session at the #IIMEC12 International Conference on 2nd June 2017. This will allow students funded by IiMER or those working in collaboration with the UK Centre of Excellence to answer questions on their work.

We also hope to have poster presentations - open to researchers who submit their work for consideration.

We hope to begin publication of the agenda as it evolves over the next month.

Our discounted early bird rates are currently available - click here

From Journal of IiME 2006

At the Invest in ME Conference held on 12th May 2006 in London, expert speakers presented their work, including evidence from Dr Jonathan Kerr from St George's University, London, that most of the abnormally expressed genes seen in (ME)CFS are involved in the immune system. The take-home message was:

- Since a prolonged inflammation is at the heart of this condition, all speakers advocated the use of the term Myalgic Encephalomyelitis, not Chronic Fatigue Syndrome, since most if not all illnesses cause 'fatigue'
- Inflammation is at the heart of ME – the immune system response is indicative of inflammation; inflammation is in the muscles and in the blood vessels
- The illness is not and never has been 'all in the mind'
- There is a genetic predisposition for ME
- ME is a legitimate physical illness and patients are really ill – their immune, endocrine and neurological systems are compromised and they should not be made to exercise
- The truth about ME is already out there, so why does widespread ignorance and misinformation remain? (Co-Cure ACT; 17th May 2006).

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Invest in ME Research

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Support ME Awareness - Invest in ME Research

FAST TRACKING SOLUTIONS FOR ME

Centre of Excellence for ME

investinmeresearch.org

Let's Cresearch!

Myalgic Encephalomyelitis (ME) is a serious, chronic neurological disease. UK Charity Invest in ME - Research (IMER) are establishing a Centre of Excellence for ME - a hub for research activity in Europe - enabling a strategy of high-quality biomedical research projects to follow, coordinated and collaborating with other institutes. Please support our C of E for ME. Let's Do It for ME. Let's C research into ME.
See http://www.investinme.org/research #CofEforME #LetsCresearch @LetsDoIt4ME

Invest in ME - Research (UK charity nr. 1153730)

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