



Invest in ME Research

NEWSLETTER



September 2016 **Newsletter**

Welcome to the September 2016 Invest in ME newsletter.

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Invest in ME Research - Let's Do Research

"Possibly the two most important research projects for ME in the UK

2017 COLLOQUIUM/CONFERENCE DATES

Did anyone see a summer around here?

We cannot believe it - but already we are planning next years' research Colloquium and Conference.

The dates for the **Biomedical Research into ME Colloquium 7** are **31st May - 1st June 2017**.

The date for the **IIMEC12 12th Invest in ME International ME Conference** conference is **2nd June 2017**.

For our foreign delegates there is some comfort from the recent Brexit vote in that prices in London should now be more attractive to overseas visitors.

In order to produce the best event we would welcome sponsorship and will actively seek out opportunities to assist us. Should anyone have contacts who may be interested then we will send our conference sponsorship brochure.

Registration for the conference will be open as soon as the new website pages are created on our conference site at www.investinme.eu



SIGNS OF A RELIABLE DIAGNOSTIC MARKER, A CHEMICAL TEST

Professor Ron Davis from Stanford presented at the recent Invest in ME Biomedical Research into ME Colloquium 6 (BRMEC6). He also presented at the IIMEC11 conference.

Following these talks a paper was published by Navieux et al in PNAS (Proceedings of the National Academy of Sciences of the United States of America) and edited by Prof Ron Davis.

They say " Metabolomics showed that chronic fatigue syndrome is a highly concerted hypometabolic response to environmental stress that traces to mitochondria and was similar to the classically studied developmental state of dauer."

The hypometabolic state of ME (CFS) has been suggested by others such as Marian Dix Lemle and Professor Harald Nyland at our 2009 conference but without any actual evidence like this to back the claims up.

The Navieux paper also addressed the many triggers leading to same symptoms conundrum and stated that "Despite the heterogeneity of triggers, the cellular response to these environmental stressors in patients who developed CFS was homogeneous and statistically robust. These data supported the notion that it is the unified cellular response, and not the specific trigger, that lies at the root of the metabolic features of CFS."

References:

Robert K. Naviaux, doi: 10.1073/pnas.1607571113
[<http://www.pnas.org/content/early/2016/08/24/1607571113.full>]

<https://health.ucsd.edu/news/releases/Pages/2016-08-29-chemical-signature-for-chronic-fatigue-syndrome-identified.aspx>

It should also be noted that the Invest in ME funded gut research [<http://www.investinme.org/LDR%20UK%20Gut%20Microbiota.htm>] includes metabolomics and it is being done independently of the above research.

There is collaboration on this within the European ME Research group (EMERG) – a meeting of EMERG was held in London prior to the BRMEC6 Colloquium.

IIME SPONSORS STUDENTS

Part of the charity's strategy for improving education has been to involve medical students in research into ME.

By participating in the research projects that the charity funds then students are able to learn far more about ME and patients as well as passing on the reality of this disease to their peers.

An example was the contribution made by Dr Navena Navaneetharaja and Verity Griffiths with this paper [<http://www.mdpi.com/2077-0383/5/6/55>] which followed their participation in the IiME funded research projects at IFR/UEA

A new medical student is beginning the new academic year by participating in our funded research projects at UEA/IFR - more at <http://www.investinme.org/LDR%20UK%20Gut%20Microbiota.htm#Aug16MedStudent>

Another student will be assisting Fane and Dr Jo Cambridge in the IiME-funded B-cell research at UCL - <http://www.ukrituximabtrial.org/Rituximab%20news-Aug16%2001.htm>

These are huge commitments for a small charity, on top of our other commitments, but essential for our plans for our strategy of finding and facilitating high-quality research and education for ME.

MedEd - MEDICAL EDUCATION FOR DOCTORS

Following the IIMEC11 conference Invest in ME organised an impromptu post-conference dinner, during which an idea was discussed with Professor Elisa Oltra and Professor Jonas Bergquist to expand doctors' knowledge of ME with a curriculum.

We initiated a group discussion at the table - and so was conceived MedEd - an attempt to standardise education about ME for doctors using a collaborative, cross-continental approach.

A working group has been set up and patient advocate Mary Dimmock has been coordinating this with representation from those present at the conference dinner. This small group

consisting of US, European and Australasian researchers, doctors and advocates continues to meet to develop an educational package that is simple but effective.

We hope for some promising developments from this group.

AUGUST UPDATES FROM LDIFME

The LDIFME team have produced an update summary for activity during August. The [link is here](#).

Our thanks to all supporters who have been making such great efforts to support us in making progress with research into ME.



The PACE TRIAL

An Appalling Episode in ME/CFS Research



The title is from Professor of Law at Northwestern University, Steven Lubet who was commenting on Professor Vincent Racaniello, Professor of Microbiology and Immunology at Columbia University, New York - in VIROLOGY BLOG.

<http://www.thefacultyounge.org/2016/08/some-readers-will-recall-my-earlier-posts-about-the-serious-flaws-in-the-pace-trial-in-which-a-group-of-british-psychiatrist.html>

It succinctly sums up this long running farce called the PACE Trial.

Invest in ME have campaigned against the PACE Trial since its inception and it is little comfort that finally this monstrous waste of public funding and human life is finally being recognised by more and more as a hallmark for mediocre research which fails to help the patients it ought to help.

TRIBUNAL ORDERS QMUL RELEASE PACE TRIAL DATA

Professor Racaniello's articles follow the news that Queen Mary's University (QMUL) in London had been ordered by the First-Tier tribunal to release the data from the PACE Trial for independent analysis.

QMUL's defiance with regard to the FOI request from patients to release the data defied any logic or integrity. Their arguments for avoiding releasing the data were spurious - and frankly risible. This tribunal centred around a request made by an Australian patient, Mr Alem Matthees, who provided well-reasoned material that the judge agreed with.

It is just a pity that a sick patient has to go such lengths to get information released from an establishment organisation that should be so simple to produce if the will was there for open data sharing.

If there is nothing to hide then what is to be lost? Unless, of course, there is indeed something they wish to hide!

As our advisor Emeritus Professor Jonathan Edwards wrote [1] -

"If scientific interpretation is poor it deserves no protection. If it is good it needs none."

QMUL also ignored The European ME Alliance's letter requesting release of the data [2].

Their attitude and behaviour has been callous and indefensible - and their reputation is, deservedly, severely damaged.

We still have to wait to see whether QMUL spends even more money on legal expenses (an estimated £202k was already spent in legal fees attempting to avoid releasing the data) and whether they seek permission to appeal to take the case to the Upper Tribunal. But it demonstrates complete disregard for patients and a level of behaviour that is scandalous.

1] <http://theconversation.com/tribunal-was-right-to-order-release-of-chronic-fatigue-trial-data-64255>

2] <http://www.euro-me.org/news-Q12016-002.htm>

MRC/LANCET LETTERS

Others who are also very good at avoiding answering letters from a UK charity are the Lancet's editor and the Medical Research Council. Invest in ME still awaiting a response from its letters to the Lancet - [3].

The Lancet ignores completely the views of ME patients.

As André Gide once wrote - "The true hypocrite is the one who ceases to perceive his deception".

However, we expected more from the MRC after the CEO wrote to us and assured us that an answer [to our letter](#) would be forthcoming.

We have therefore written again to Sir John Savill at the MRC and requested an answer - [click here to read](#) our new letter to the MRC CEO.

AHRQ DOWNGRADES EVIDENCE FROM CBT/GET STUDIES

More fallout from the PACE Trial in the wake of the First-Tier Trial judgement appeared when the Agency for Healthcare Research and Quality U.S. Department of Health and Human Services (AMHRQ) provided more good news and supported patients' long held views that the evidence from CBT and GET studies using the so called Oxford Criteria (used in the PACE trial and many other CBT GET studies) could not be used as evidence to declare that CBT and GET are evidence based treatments for ME/CFS.

AHRQ also stated [in their report](#) -

“As a result, using the Oxford case definition results in a high risk of including patients who may have an alternate fatiguing illness or whose illness resolves spontaneously with time. In light of this, we recommended in our report that future intervention studies use a single agreed upon case definition, other than the Oxford (Sharpe, 1991) case definition. If a single definition could not be agreed upon, future research should retire the use of the Oxford (Sharpe, 1991) case definition.”

This decision follows excellent work performed by US advocates Mary Dimmock and Jenny Spotila.

More can be seen from Jenny's blog - <http://occupyme.net/2016/08/16/ahrq-evidence-review-changes-its-conclusions/>

MARGARET WILLIAMS REPOSITORY

What we are witnessing now is the gradual destruction of the flawed and negligent perception of ME which vested interests have created for the last decades and which has so pervasively influenced government departments, academia, medical establishments, the media and, by eventual lemming-like acceptance, the public.

The flagship of the those who have promoted (and benefited) from the biopsychosocial view of ME for so long has begun to sink, run aground on the rocks of reason, science and an intractable dedication from some patient organisations and patient advocates. The wreck that is PACE is dragging down those pillars of the establishment that have supported it.

For so many years when establishment organisations and individuals have been following a false path of research and treatments for ME, supported by fickle media editors and buffoon journalist hacks, there was a constant source of factual information and analysis about ME - a voice of science and reason and factual information which gave the lie to the biopsychosocialists.

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This came from Margaret Williams - a severely affected patient who saw through the falsehood of the myths perpetrated by vested interests and produced countless articles exposing the corrupt environment maintained by the establishment toward ME.

Invest in ME has featured many of Margarate Williams' articles during its 10 years as a charity.

Now all of her articles have been indexed and made available online at this url - www.margaretwilliams.me

Not only indexed but also containing a search button so once can search on any topic, organisation or individual easily.

This is a resource which will be of historical significance for academics - and a huge testament to one of the great ME advocates.

This will likely be the last newsletter sent from Invest in ME.

The charity is moving to a new charity format and will be using the name **Invest in ME Research** for future newsletters - and on our new web site.

The old newsletters will be updated and made available still however.

[Go to Newsletter Home Page](#)

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Let's  research!

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

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