



# Invest in ME Research

# NEWSLETTER



## July 2017 Newsletter

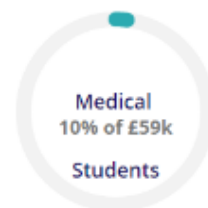
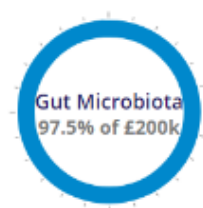
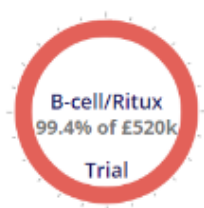
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Welcome to the July 2017 newsletter from Invest in ME Research.

### Our Current Funding Streams

Please click on the progress circles below to see the options to contribute to these funds and donate if possible.



## **NICE Guidelines Consultation – Misinformed or Cynical?**



The NICE decision "to not update the NICE guideline on chronic fatigue syndrome/myalgic encephalomyelitis" at this time seems to be an error of judgement based on misinformation. That is clearly so.

Yet on delving deeper one begins to see something more from what must have been a pre-determined decision made some while ago.

Their decision to bring forward a review to this summer, when many people are away on holiday, when parliament is recessed and with only two weeks for patient organisations to be able to respond is, frankly, a cynical attempt to keep ME buried in the world of Biopsychosocial (BPS) fantasy - as a prelude to submerging it into a swamp of Multiple Unexplained Symptoms (MUS) and Functional Neurological Disorders (FND).

The NICE review document has clearly been dominated by BPS proponents and NICE may feel themselves secure enough to use the crock of anonymity for their "Topic Experts" who have decided that ME patients' lives are worth nothing.

It should not escape notice that the number of papers springing up to justify CBT and GET for ME, and the NICE reliance on the already disastrous FITNET and thoroughly discredited PACE Trial, is being used to hurry through a biased review by the Cochrane group - all ahead of possible good news coming next year of the Norwegian Phase III rituximab trial.

By burying guidelines for ME for another 3-5 years it maintains the BPS influence and stranglehold on ME - a tactic employed by numerous false MRC "expert panels", apathetic Chief Medical Officers and a corrupted Department of Health view of ME over the last decade.

Moreover, by sneakily introducing FDN in order to pave a way to MUS clinics that seem to be opening, and including ME/CFS in those, it is a cynical move from another establishment organisation that cannot be trusted.

Transparency and the welfare of patients seem not to be priorities.

The NICE surveillance proposal for guidelines for CFS/ME cannot be seen in isolation but as part of a corrupted healthcare system dominated by forces which, as yet, seem to be unanswerable to anyone.



## *Invest in ME Research* Comments on NICE Guidelines Consultation Review

Invest in ME Research submitted an 8000 word response to the consultation review. Having read the whole document it became clear to us that there was little point in being nice to NICE or to give support to organisations such as cmrc & MEGA that seem to us to have been set up to delay any real progress and keep people busy and forever hopeful.

We prefer to say it straight and not play along the silly establishment games which merely maintain the healthcare scandal typified by the PACE Trial, embellish the egos and careers of some commentators and keep patients in the scandalous status-quo.

Read our [submission to NICE here](#)

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### **New ME/CFS Pediatric Primer**

A new ME/CFS Pediatric Primer has been published. It was written by an international group of pediatric experts and is freely available.

Available here - <http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full>

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### **Norwegian Research Funding**



Good news from Norway of new research being funded - with all having to be based on Canadian-criteria - and some dubious applications for funding being completely rejected.

The Norwegian Research Council has listened to the patients this time, and even participated on Invest in ME Research [Colloquium](#) and [Conference](#) in London in order to get an overview of the field.

[https://www.forskningsradet.no/no/Nyheter/Her\\_er\\_MEpasientenes\\_forskningsprosjekte\\_r/1254027496285](https://www.forskningsradet.no/no/Nyheter/Her_er_MEpasientenes_forskningsprosjekte_r/1254027496285)



## IIMEC12 Conference DVD

The DVD of the IIMEC12 Conference is now being distributed.

Containing all of the conference presentations, as well as the pre-conference dinner speech by David Tuller, this educational DVD is a must for healthcare staff, researchers and patient groups.

The DVD has already been distributed to eighteen countries - including our first time delivering to Brazil.

[Use this link](#) to order



## BBC programme



The BBC Radio 4 programme on ME turned out to be a wasted opportunity for investigative journalism.

The programme was broadcast on 27<sup>th</sup> June but has now fallen into the box labelled inconsequential - having done little to move us forward! And, for some, an exercise in hypocrisy.

When the programme had the possibility of hearing from international researchers and clinicians – and actually was allowed access to interview some at BRMEC7 and IIMEC12 – then this represents another exercise in treading water on this subject.

The extent of this problem was not described – neither was the international dimension.

But, especially, the real causes behind this scandal were not even looked at.

It was clearly a safe approach and the reasons for the problem were not covered.

<http://www.investinme.org/IIMER-Newslet-1706-01.shtml>

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## BEN SCOTT RUNNING FOR IIMER

Ben Scott is another marathon runner raising awareness of IIMER and the need for biomedical research into ME.

Ben is running two in August – an amazing feat.  
We have some great people running for the charity

Ben's fundraising page and story is here  
<https://www.justgiving.com/fundraising/benruns4me>

And his facebook page has more information –  
<https://www.facebook.com/BenRuns4ME/>



## ROYAL PARKS HALF MARATHON



## INVEST IN ME RESEARCH

Invest in ME Research have secured three places in the Royal Parks Half Marathon on **8th October 2017** - and we would love to hear from anyone who would be willing to raise funds for biomedical research, and awareness of ME, by representing the charity in this event.

More details [at this link](#).

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## CURRENT FUNDRAISING



Huge thanks from iIMER to all those who have been helping to fund-raise and raise awareness for the charity. Also to all who have donated to the various funds for biomedical research.

We welcome new help in fundraising for our research - as well as expressing thanks to those who are, or have been fundraising.  
Some of these are shown in the following links -

[Current fundraising campaigns](#)

[Previous fundraising campaigns](#)

One exceptional example of fundraising was from Helen Oliver and her amazing Move ME which raised an astonishing £12878  
[\[https://www.justgiving.com/fundraising/helen-oliver15\]](https://www.justgiving.com/fundraising/helen-oliver15).



And another just finishing is Catherine Clapton - who has swum in 30 bays in 30 days -



<https://www.justgiving.com/fundraising/catherine-clapton2>

## The PACE Trial



The saga of the discredited PACE Trial will, hopefully, be in its last stages of existence. Though NICE is still so heavily influenced by BPS fundamentalists even they cannot stop the mounting opposition to this flawed trial.

On 31<sup>st</sup> July a press release will be published for a forthcoming Editorial for a Journal of Health Psychology Special Issue on the PACE trial-A Medical Scandal.

Editor of the JHP David Marks has commented –

"The Trial attracted unprecedented criticism, not only because it cost taxpayers an extraordinary sum (almost £5 million) but the trial itself was deeply flawed. The results are, at best, unreliable, and, at worst, manipulated to produce a positive-looking result."

Yet even now it seems forces are intent on trying to stop publication of any criticism of the trial - reflecting what many have suspected for a long time - that insidious and corrupt manipulation and influence is and has been exerted over any who do not passively accept the results from this trial.

All through the existence of the PACE trial patients and academics arguing for the retraction of the PACE Trial have been met with establishment attempts to thwart, deny or block any argument against the flawed PACE Trial or the authors.

This JHP piece seems to have been no exception with apparently last minute attempts to stop publication on the grounds that the JHP submissions/papers were not properly peer reviewed (ironically exactly the thing PACE authors were opposed to for their submissions elsewhere).

David Marks tweeted -

"Last ditch attempt to block publication by #PACEtrial advocate foiled.

Weasely coward suggested papers weren't properly reviewed. All were."

As our advisor Professor Jonathan Edwards has commented -

"The strength of certain people's conflict of interest becomes very clear when attempts are made to block publication of a series of very reasonable and well-argued papers dealing with quality in science."

We shall see if this really is the end of this disgraceful paper.

The JHP Special issue can be seen here -

<http://journals.sagepub.com/doi/full/10.1177/1359105317722370>



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## Petition to the Dutch Health Council

Invest in ME Research invited the Dutch Health Council to the 2017 conference events in London - and, sharing much in common with UK establishment organisations, they did not reply.

Perhaps this may get their attention - <https://meisgeensolk.petities.nl/?locale=en>

A Dutch petition - **ME is not MUPS: Change Dutch Health Council Committee and adhere to the advisory report assignment**

The Dutch Guidelines are based on NICE - and have been made part of a broader Medically Unexplained Physical Symptoms (MUPS) guideline.

As the Dutch advocates state -

'BPS proponents/Dutch PACE colleagues with vested interests, who are still advocating CBT/GET as safe and effective and as the only "evidence based"



treatment, should have no place in deciding future health policy for ME patients and how to spend valuable research money.'

The Dutch Health Council report will go to parliament and determine the care and research spending for the next decade - a similar corrupted scenario being shaped as was planned for the UK.

The Dutch are suffering in the same way as UK patients by the negligence and flaws in establishment organisations – and the apathy of government departments who should be demonstrating responsible management of the problem.

1200 signatures are needed to reach the goal of 10,000.

<https://meisgeensolk.petities.nl/?locale=en>



Photo: Bente Kubin

(One can sign from any country with name or anonymous, but do not forget to click on the confirmation link in the email after signing).

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## IiMER Informational Postcards



Use our informational postcards to make doctors aware of the charity and our work. Available from Invest in ME Research by contacting us at [info@investinme.org](mailto:info@investinme.org)

*Invest in ME Bear*

## New Wristbands for Awareness

Our new wristbands are available.

Make a mark for ME awareness by using or giving one of these.



How to order – [click here](#)

## Articles on ME/CFS by Margaret Williams and Professor Malcolm Hooper

Articles on ME/CFS by Margaret Williams and Professor Malcolm Hooper

1986-2017

With contributions from Eileen Marshall (1994-2007) and others

[1986](#) | [1989](#) | [1994](#) | [1995](#) | [1996](#) | [1997](#) | [1999](#) | [2000](#) | [2001](#) | [2002](#) | [2003](#) | [2004](#) | [2005](#) | [2006](#) | [2007](#) | [2008](#) | [2009](#) | [2010](#) | [2011](#) | [2012](#) | [2013](#) | [2014](#) | [2015](#) | [2016](#) | [2017](#) |

A collection of articles by Margaret Williams and Professor Malcolm Hooper together with related documents written by other people (for example, the Countess of Mar, Professor George Szukler, Professor Simon Wessely, Professor Michael Sharpe, as well as official reports and the PACE trial protocol). These articles have been available on the internet or elsewhere for many years but now for the first time have been brought together in one place. The intention is to provide a valuable historical resource for researchers, advocates, patients and anyone interested in the illness Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. These articles illustrate how the "Wessely School" have ignored the biomedical science on ME/CFS for almost 30 years.

**Margaret Williams** is the pen-name used by someone who spent her professional life in the British National Health Service (NHS), latterly in a senior clinical capacity for many years until severe ME put an end to her career. For professional and personal reasons she does not wish her own name to be in the public domain.

**Malcolm Hooper** is Emeritus Professor of Medicinal Chemistry at the University of Sunderland in the UK, and is an advocate for ME/CFS patients. He chaired the [International Invest in ME Conference](#) in 2008, 2010, and 2011. Professor Hooper is also the Chief Scientific Adviser to the UK National Gulf Veterans Association and President of the NGVFA.

There is comprehensive INDEX at the [bottom of this page](#). Articles in **bold** are considered important or significant.

Search this catalogue:

site search by thefind [advanced](#)

Click on "PDF" to read each article. Most browsers open pdf files within the browser. To bring up the article in a separate tab, hold down Ctrl while clicking on "PDF". To save to your computer, right click on "PDF" and choose "Save link as", or "Save target as".

## Dr Bruce Carruthers



The sad news came of the passing of Dr Bruce Carruthers.

Bruce was a dedicated physician who did much to help the ME community.

The image here was Bruce speaking at our IIMEC1 conference in London in 2006.

Thank you Bruce - RIP

[Go to Newsletter Home Page](#)

[\*\*#CofEforME\*\*](#)

[\*\*#letsCresearch\*\*](#)

## Invest in ME Research

UK Registered Charity Nr. 1114035  
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***Support ME Awareness - Invest in ME Research***



**FAST TRACKING SOLUTIONS FOR ME**



**of Excellence for ME**

*[investinmeresearch.org](http://investinmeresearch.org)*

**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

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

[www.investinme.org](http://www.investinme.org)

email: [info@investinme.org](mailto:info@investinme.org)