



# ***Invest in ME Research***

# **NEWSLETTER**



## **June 2017 Newsletter**

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Welcome to the June 2017 newsletter.

***Invest in ME Research - Let's Do Research***

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

**Invest in ME Research Conference Week  
The Best Yet?**



The 2017 Conference week has ended.

With four days and evenings of events the charity has now facilitated another set of meetings which have broadened and bolstered the foundations of international biomedical research into ME, which have been laid for the last twelve years.

The two-day Colloquium, now in its seventh year, has researchers from the main centres around the world discussing, sharing, innovating, and collaborating on research into this disease which will help all patients and their families around the world.

The Colloquiums are unique and we are confident that this model is the correct one for continuing to make rapid progress in order to find the cause(s) of ME.

The atmosphere this year was especially good and we already know of potential collaborations in research which are forming or have formed.

We are working on a report from the Colloquium which we hope to make available for all.

## #TearItUp

David Tuller gave a forceful pre-conference dinner speech which left nobody in doubt as to the problems with the PACE Trial.



How this particular piece of research is still being defended by some, and how certain others maintain an overwhelming silence over the support of the trial, is beyond comprehension.

David ended his presentation by bringing the title of the speech to life. The PACE Trial, and other papers which were deemed unusable, were left in pieces on the floor.

*Fiat justitia ruat caelum*

Following the pre-conference dinner David has put out a crowdfunding campaign to secure his continuing investigation of the PACE Trial and similar research which have been heavily criticised by patients.



As David writes –

"That's why I am seeking your tax-deductible contributions for another year of investigating and blogging about the PACE trial and ME/CFS on Virology Blog. I will also continue to write articles for other publications, when possible. There is much, much more investigating, blogging and hammering away to do--about conflicts of interest, about the FINE "sister" trial, about Cochrane's misleading systematic reviews, the false PLoS One claim that the treatments are "cost-effective," etc, etc. "

David needs just \$15000 at the time of this newsletter.  
More on this [at this link](#)

## IIMEC12

The 12th Invest in ME Research International ME Conference was sold-out well before the event started.

IiMER not only hosted and arranged the conference but we also had our own stand manned throughout the conference day by volunteers.

This introduced our *UK Centre of Excellence for ME* banner.

Also exhibiting was Quadram Institute Biosciences where several PhD students are performing research into ME funded by Invest in ME Research.



We also invited a Norwegian company - No Isolation - to exhibit.





This company is dealing with some of the major consequences of a disease such as ME - isolation and exclusion and ignorance of the disease.

By using a device to allow a spirit of inclusion to be developed and maintained then children are not ignored by schools.

This is something IiMER is very passionate about and we welcomed the chance to help highlight this issue.

More in our [conference Journal](#).

## @MikesEUmaras

Mike Harley also attended with his own life-sized banner.

Mike is running 28 EU marathons in support of Invest in ME Research and has already completed 10 of them.

Mike continues with his incredible marathon programme with the next event in Lithuania in September.

More details here at the link below  
<http://investinme.org/ce-IIME-Newslet-1504-02.shtml>

Mike's JustGiving [page is here](#)

Mike had just completed the Luxembourg marathon – though one would not have known it by looking at him.

The next marathon for Mike is Lithuania in September.

Apart from raising funds and awareness for the charity's biomedical research and Centre of Excellence Mike is also writing about conditions in each country for people with ME. This provides a valuable insight into problems occurring locally.



Mike's reports can be seen by clicking on the images in the table on this page  
<http://investinme.org/ce-IIME-Newslet-1504-02.shtml>  
Or by visiting Mikes Blog here -<http://www.mikeseumarathons.eu/>

Some notable guests came past the stand -



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**IIMEC12 Conference Summary Page**  
<http://www.investinme.eu/iimec12.shtml>

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## **BBC Colloquium Interview Arranged by IiMER**

IiMER were responsible for facilitating interviews by the BBC for an upcoming radio programme about ME.

After being contacted by the BBC journalist for a programme which seemed to be already in an advanced stage of preparation we attempted to provide more substance by using the scientific knowledge present at our Colloquium.

IiMER prepared these interviews by selecting a good cross section of scientists, researchers, clinicians and a parent of severely affected children with ME. And so interviews were conducted, at very short notice, during lunch on day 2 of the Colloquium - and more interviews followed the next day with Nigel Speight and David Tuller at our Conference, at our invitation to the reporter.

What surprised us most though was that, whichever sources of information had been used before in preparing for this programme, none had given any information regarding our Colloquiums or Conferences, nor of our attempts to create a base of biomedical research for ME in Europe.

And there was no awareness of the top researchers or even the Norwegian rituximab research and trials.

It was fortunate that IiMER created the opportunity to make the reporter aware of these.

It would be advisable for the BBC to revise their "preferred" sources of information (which seem to be always a standard set of charities, organisations or individuals) who are feeding BBC journalists regarding ME.

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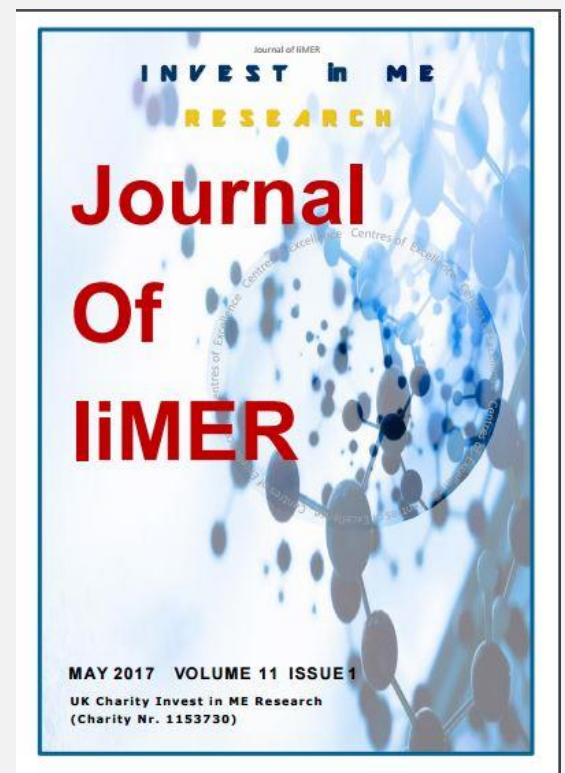
## **Journal of IiMER**

We issued our conference Journal online during the conference as well as each Colloquium/Conference delegate receiving a printed copy.

This can be accessed here using the link below - in pdf or flipbook form - click on the image to the right.

<http://investinme.org/journals.shtml>

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## Conference DVD

All of the presentations from the conference will be available on the conference DVD - able to be ordered via this link

- <http://www.investinme.eu/iimec12.shtml#dvd>

## European ME Alliance News



Following the conference and colloquium events Invest in ME Research hosted the European ME Alliance (EMEA) Annual General Meeting.

Two new members have joined EMEA.

Representing France as a full member is **L'Association Francaise du Syndrome de Fatigue Chronique.**

Joining as an Associate member is **Hope 4 ME & Fibro Northern Ireland.**

These additions bring the total number of members to 15 and the total number of countries to 14 in Europe.

<http://www.euro-me.org/news-Q22017-002.htm>

EMEA also had a table at IIMEC12 in London attended by Nancy Van Hoylandt from EMEA Belgium.





Two EMEA conferences are planned for the autumn - one in Iceland and one in Stockholm.

The respective EMEA groups organising these are [ME FÉLAG ÍSLANDS](#) and [Riksföreningen för ME-patienter \(RME\)](#).

More details later.

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## **Dangerous exercise. The detrimental effects of exertion and orthostatic stress in Myalgic Encephalomyelitis and chronic fatigue syndrome**

An article from Frank Twisk (the EMEA Holland representative) has produced an article and a timely reminder that graded exercise protocols seem to have detrimental effects on many patients.

<https://oatext.com/dangerous-exercise-the-detrimental-effects-of-exertion-and-orthostatic-stress-in-myalgic-encephalomyelitis-and-chronic-fatigue-syndrome.php>



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## **IIMER Scientific Advisory Board Update**



We are very pleased and honoured to announce that Anne Cooke, Emeritus Professor of Immunobiology at University of Cambridge, has agreed to join the advisory board of Invest in ME Research.

Professor Cooke attended our BRMEC7 Colloquium and IIMEC12 pre-conference dinner recently.

Our advisory board [is listed here](#)

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## Failure is an Option



The UK Medical Research Council is preparing to be absorbed into the new UK Research and Innovation body which will incorporate the seven Research Councils, and other organisations and the MRC CEO will move on to another post.

The NHS National Medical Director will also move on to another job at the end of the year.

Both organisations have had leaders who have been in their posts for a relevant period - a time where change could have been made to policies concerning research and treatment into a disease which has been neglected for a generation.

These officials will move on to new roles.

And what of ME?

The answer is that it does not register on either of the radars of these men who have overseen ME research and treatment in UK for the last years.

Having attempted on many occasions to engage with the MRC, NHS and DoH on the subject of ME then we see another chance lost.

And perhaps a new opportunity emerging.

Read more - [click here](#)

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## UK CENTRE of EXCELLENCE for ME PLANS

The pace of research continues at the UK CofEforME with adverts out for a Senior Research Associate for work leading to the UK rituximab trial and a new PhD studentship being funded from the autumn.

Our great thanks to the **Hendrie Foundation** for their support with this.

As mentioned before we hope to fund more medical students to participate in research by intercalating in their medical studies for a year.

The charity is committed to this objective of forcing change by a dedicated Centre and international collaboration and we are pleased to see more and more support coming forward for our strategy.

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**[#CofEforME](#)**

**[#letsCresearch](#)**

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Our aim is to ensure that a strategy of biomedical research produces results as quickly as possible.

For this we need help and support - this is the best opportunity for UK and European research.

We invite support to raise funds and awareness for this enterprise.

Our thanks to all those who have donated to the Centre of Excellence, the gut microbiota studies, the medical students and to our research fund. Also to those who have donated or pledged funds for the rituximab trial/B-cell research - including organisations and individuals from around the world - with no strings attached but just a wish to have high-quality biomedical research carried out.



The other research at the Centre - which started with the foundation project - is underway - [more details here](#).

It is good to see that more acceptance and support of the UK Centre is increasing.

However, we do welcome more support - ways to help us are [here](#) or our Big Give link [here](#).

[Read more](#)



## CURRENT FUNDRAISING

There are so many people whom we need to thank for supporting the charity and the strategy of high-quality research and international collaboration that we are pursuing.

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](#)



investinme.org    ldifme.org

IS THIS WHERE THE CAUSE OF ME LIES?  
UK Gut Microbiota Project II

We'd like to find out!

**New Total**

**£190,000**  
Target = **£200,000**

Invest in ME Research - Let's Do It!

Invest in ME (UK charity no. 1114039)  
www.investinme.org    email: info@investinme.org

Small Charity  
GDS Count  
2017

## IiMER Bear

Our mascot (created by Jan Laverick) has his own Instagram account - and he is showing no inhibitions in demonstrating how indispensable (he thinks) he is.

Join IiMERBear for news of what he (and his minions) are doing to progress research into ME.



<https://www.instagram.com/iimerbear/>

A last word from the bear

'Hello everyone!  
I'm here to make sure my minions do the best  
job they can.

Any complaints, address it to them.

Any praises, send them to me  
([iimerbear@investinme.org](mailto:iimerbear@investinme.org)).

Looking forward to working with you!"

*iIME Bear*



Hmmm!

It must be hunting season soon!



[Go to Newsletter Home Page](#)

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**UK**

***Support ME Awareness - Invest in ME Research***





**FAST TRACKING SOLUTIONS FOR ME**



**of Excellence for ME**

***investinmereresearch.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)

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