

**Welcome to Invest in ME's May 2011 newsletter**

## **ME Awareness Month 2011**

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### **Burst Our Bubble - ME Awareness Month 2011**

For ME Awareness Month we introduced our Burst Our Bubble campaign.



People who suffer from Myalgic Encephalomyelitis (ME) are forced to live in a bubble - a bubble formed from -

- Misinformation
- Medical ignorance
- Misdiagnosis
- Discrimination
- No funding for biomedical research
- Government apathy
- Isolation

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Our web page [is here](#).

IIME have prepared leaflets which can be downloaded (in black or white versions). We also have these available for groups or individuals who are interested in promoting the campaign - subject to funds being available to cover costs.

([Why ME Awareness MONTH - click here?](#))

What is happening during May? Invest in ME's efforts for promoting awareness in May is the Burst Our Bubble campaign, an advert in a leading London magazine (see later), a major presentation in London on **Science, Politics and ME** and the International ME/CFS Conference 2011 which provides a platform for the latest biomedical research into ME from the world leading experts. We shall also be hosting the 2011 AGM of the **European ME Alliance**.

Amongst IIME's events are the following -

### London Business Matters

IIME were selected as Charity of the Month by London Business Matters (The official publication of the London Chamber of Commerce and Industry) and we are making use of this opportunity by taking out a full page advertisement to raise awareness of ME. This will allow us to raise awareness of ME by reaching 18,000 decision-makers in London. We hope we can gather support for future research and raise awareness of the lack of attention and funding which is being given to proper research into ME. [See this link](#).

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### Pre-Conference Evening Presentation - 19<sup>th</sup> May

The pre-conference evening - **Science, Politics...and ME** - will provide a platform for raising awareness of the politics which has, and is affecting the lives of hundreds of thousands of patients on both sides of the Atlantic by thwarting biomedical research. The recent PACE Trial is an example of a flawed study which has been allowed to be funded yet has no meaning in the real world.

This year Dr Ian Gibson will join US journalist Hillary Johnson, author of Osler's Web. Hillary's presentation at our pre-conference presentation of 2009 (when she spoke of the CDC and its influence worldwide) is still available on DVD [[available on the 2009 DVD here](#)].

This pre-conference event is full but we will maintain a waiting list.



We hope to film this event for a subsequent DVD (see later new item).

### IIMEC6 - The 6th Invest in ME International Conference 2011 - 20th May

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Our Thanks to The Irish ME Trust - sponsors of a speaker at the 6th Invest in ME International ME/CFS Conference 2011.

The Irish ME Trust has again agreed to sponsor a speaker at the Invest in ME International ME/CFS Conference 2011. Invest in ME want to thank IMET for their generosity which allows us to continue to organise and host this event.

The emphasis at the IiME 2011 conference is on the need for clinical trials into ME. Many (most) physicians in the UK are unaware of biomedical research into ME and of the possible treatments which may be available. More research is required and more clinical trials need to be organised.

ME Awareness Month draws to a close with the major biomedical research conference in London focusing on clinical trials of ME. We hope this year will be a very special and memorable occasion.

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### More Conference News

We hope to be able to include an additional speaker at the conference. Keep a look-out on the conference news page ([click here](#)).

Our colleagues from the European ME Alliance will again be present. Eighteen countries are now represented at the conference - but the Chief Medical Officer of England will not be.

The refusal by the Chief Medical Officer in the UK to attend yet another IiME biomedical research conference means that the Department of Health's main advisor is again unaware of the differences which could be made to establish a credible government policy toward ME. Our question always is how much more embarrassing can it get for the CMO? Dame Sally Davies is the first woman to hold the role of CMO and one could have expected a more proactive approach to an illness which affects the lives of so many. One of her roles is –

**to provide, clear, independent and evidence based advice to the Secretary of State for Health and the Government on all matters relating to the nation's health and on clinical aspects of the National Health Service**

We doubt this is possible with regard to ME if she is not able to make it to a major biomedical research conference on her doorstep.

There is still a place available for the CMO if she changes her mind.

We have written to the chair of the APPG for ME and offered to facilitate a meeting with MPs prior to the IiME conference in Westminster on 20th May. IiME have proposed a meeting and organised a venue close to parliament for this to occur and we are awaiting news on that meeting at this point in time. This is IiME's attempt to allow clear and up-to-date information on biomedical research into ME to be presented directly to MPs who have a wish to change the direction of research and treatment of ME.

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IiME will also be able to present its proposal for an examination and research facility to be set up in Norfolk ([see here http://www.investinme.org/Research%20-%20ME%20Institute.htm](http://www.investinme.org/Research%20-%20ME%20Institute.htm)).

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### Journal of IiME

A conference version of the Journal of IiME will also be published in May and will be available, for free, via this link - [click here](#). This edition has will also serve as part of each delegate's conference pack.

### Conference DVD

We hope to be able to offer the conference DVD with a special early bird price for the month of May. Keep a look-out on the web site for this offer. The conference proceedings will be available together with the pre-conference evening presentation with Dr Ian Gibson and Hillary Johnson.

### Lost Voices for a GP - 1st - 31st May

During the month of May Invest in ME will be further subsidising our Lost Voices book by offering it for just £5 (UK, prices different for outside UK) when purchased for a healthcare professional or department. The idea is to allow healthcare professionals to be aware of the effects of severe ME as well as read of the facts about ME from Professor Leonard Jason, Annette Whittemore, Dr John Chia and others. IiME have previously distributed copies to medical libraries thanks to the efforts of our supporters.

The new price of the sponsor a book appeal will be set during May [via this link](#) and IiME will arrange for the book to be sent direct to the healthcare professional or department concerned with details of where it came from, if desired.

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### Letter to The RCPCH

The Royal College of Paediatrics and Child Health recently had published its submission to the NICE Guidelines for ME Review. In this submission it perhaps showed its true colours by including the statement that "Regarding the epidemiology of chronic fatigue syndrome: as a psychological illness with physical manifestations".

Invest in ME challenged the chairman of the RCPCH by writing a letter to him (see <http://www.investinme.org/IIME%20Letter%202011-04%20RCPCH.htm>).

The RCPCH finally rescinded their statement where they stated they

"....have reviewed our submission to the NICE consultation and can confirm this comment was from one individual who assisted in our response. As such it does not represent RCPCH policy, and in retrospect should not have been included. The phrase "as a psychological illness with physical manifestations" was unhelpful... reassure you RCPCH continues to view this condition as a biological illness" -Dr David Vickers

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We are glad that following this letter the RCPCH have publicly stated that the erroneous statement was an error and that they have retracted this. It remains to be seen if the person(s) responsible for this erroneous statement are prevented from spreading this misinformation among their colleagues.

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### Letter to The Lancet

The Editor of the Lancet recently participated in an Australian radio broadcast which included proponents of the PACE Trials. The comments by Dr. Richard Horton indicate a lack of knowledge about this disease and about the biomedical research which has taken place and is continuing, even though it receives none of the funding which psychiatrists have received to promote their flawed research. Invest in ME therefore invited Dr Horton to the IIMEC6 conference on 20th May as our guest -

<http://www.investinme.org/IIME%20Letter%202011-04%20Lancet.htm>

Dr Horton has since declined the offer as he is in attending another conference. So Invest in ME have offered a place to any editor of the Lancet so that they may be appraised of the biomedical research into ME and may then be in a position to report accurately on ME in the future.

Ignorance is not an option.

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### "Grey" Information About ME/CFS

These recent events illustrate how establishment organisations are unable to adapt and accept the current knowledge regarding ME.

Much of this is due to the biased policies of the MRC aided by misinformation being presented to the media and to ministers.

Margaret Williams has produced the first part of a new article on how the media is being manipulated - [click here](#) -

<http://www.investinme.org/Article422%20Grey%20Information%20about%20ME%20CFS.htm>

"There is a wealth of important information about ME/CFS in the grey literature that has been largely ignored by those intent on denying the existence of ME/CFS as an organic disorder. Indeed, the UK NHS Policy Plus Guidance "Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline" (2006/273539 / DH Publications) with which the three Principal Investigators of the PACE Trial (Professors Peter White, Michael Sharpe and Trudie Chalder) were involved states that the grey literature on "CFS" was not comprehensively searched in the preparation of that national guideline."

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"Why are the UK patients' support charities not vigorously refuting the false reasoning of the Wessely School about ME/CFS on every possible occasion instead of colluding with it?"

Responses from ME organisations have ranged from justifiable criticism through to support for the PACE Trial and even silence from some. We hope that the carrot of MRC research funding has not created this silence regarding the PACE Trial which would be a dangerous and short-sighted approach given the history of MRC policy toward ME. Buying silence in this way might well be one of the objectives of the somatoform lobby.

The reporting of the flawed and bogus science of the PACE Trial is indicative of the misinformation which has been allowed to occur.

As Margaret Williams commented in another article -  
"People genuinely cannot understand how individuals who profess to be speaking up for the primacy of science can defend, let alone promote, such a transparently flawed study as the PACE Trial."

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### Irish Blood Ban

The Irish Blood Services have banned blood donations from people with ME.

The Irish ban actually came into force on 9th August 2010, which pre-dates the UK ban in November 2010.

European ME Alliance (EMEA) member IMET had sent a letter to the Irish CMO in October 2009 and there was an EMEA letter dispatched to the then Minister for Health Mary Harney in April 2010. No replies to these letters were forthcoming.  
Here is the statement from the Irish blood services

..you cannot give blood if you currently have Chronic Fatigue Syndrome (CFS) or if you have had it in the past. CFS is also known as M.E. (Myalgic Encephalomyelitis) and Post Viral Fatigue Syndrome.

Prior to early August 2010 donors who had a history of CFS/ME could give blood, provided that they had completely recovered and were feeling well.

On 9th August 2010, we introduced a permanent exclusion for donors who have ever had CFS/ME even if they had fully recovered. We changed the guidelines because:

**Donor Safety:** CFS/ME is a condition where people can relapse and become ill again. We were concerned that there was a theoretical risk (i.e. a very small risk) that donating blood could make symptoms worse or provoke a relapse.

**Recipient Safety:** Scientists have recently identified a possible link

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between CFS/ME and a virus called XMRV. A lot of research is being done in this area at present, and the results are conflicting. Some studies have found no link between CFS/ME and XMRV. Even if further research proves that there is a definite link between CFS/ME and XMRV, this does not mean that the virus causes the disease. Despite the fact that the link has not been proven, we took the decision to change our guidelines, as a precautionary measure, to protect blood recipients (i.e. patients who receive blood) until more is known about XMRV. We will keep abreast of developments in this area and will review our guidelines if further data become available.

Unlike the UK authorities the Irish have stated what people with ME and their families have known all along - that a ban is to protect recipient.

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Best Wishes to all,

## Invest in ME

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Follow us on Facebook - [click here](#))

## Fundraising for Invest in ME

Our fundraising page is here - <http://www.everyclick.com/investinme/info>

Our EveryClick page is here <http://www.everyclick.com/investinme>



We still have wristbands for sale to help raise awareness and fund biomedical research - [click here](#).

Please pass on information about these wristbands to support our biomedical research fund.

They are a simple and easy way of 'advertising' ME and the need for biomedical research funds.

Follow us on Facebook - [click here](#))

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# NEWSLETTER

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Please go to <http://www.everyclick.com/uk/invest-in-me/396708/0> to do all your searching as this helps us continue campaigning for ME/CFS patients and their families.



An easy way to help Invest in ME whilst shopping is provided by Easyfundraising.



Click on the [link here](#) to get to Invest in ME's page. Easyfundraising provides a FREE service where you can shop with your favourite online stores and at no extra cost raise funds for Invest in ME. You still shop directly with each retailer as you would normally, but simply by using the links from this site first, each purchase you make will generate a **cashback donation** to Invest in ME.

### **Support Invest in ME - support biomedical research**

#### **Contacts:**

#### **Inquiries**

All inquiries to Invest in ME - [info@investinme.org](mailto:info@investinme.org)

#### **Plaintext Newsletter**

To order our plain text newsletter send an email to [info@investinme.org](mailto:info@investinme.org) and entitle your email **Plaintext Newsletter**.

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**RSS**

Link to the home page. Read more on [RSS here](#).

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