



NEWSLETTER

Welcome to Invest in ME's March 2012 newsletter

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Welcome to the Invest in ME March 2012 newsletter. It has been a while since we last published a newsletter due to various circumstances. We hope we can now resume this regular monthly newsletter. We would like to thank all of our supporters who have continued to work with us to ensure progress is being made in the research, treatment and perception of myalgic encephalomyelitis.

7th Invest in ME International ME/CFS Conference 2012

The 7th Invest in ME annual biomedical research conference to be held in London on Friday 1st June 2012 has once again been awarded full CPD accreditation (6 points).

Please make sure your GP, hospital consultant and local clinic is aware of this opportunity to learn about the biomedical basis of ME. The Invest in ME conference is an ideal opportunity for healthcare professionals to meet leading ME researchers and clinicians and to learn from them to be able to provide the correct patient care.

There is no better opportunity than this in the UK or Europe to meet and hear from experts in ME and relevant ME related disciplines. Anyone interested in attending the Invest in ME conference on 1 June is reminded that the early bird discount expires on 16 March.

More information about the conference and how to book can be found here - [click here](#)

Please contact us if you want us to send you flyers and posters to distribute or you can download them - [click here](#)

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We are pleased to be able to announce that The Irish ME Trust (IMET) have once again offered their support to the Invest in ME conference by sponsoring a speaker.



Conference Agenda

Our conference line-up is available [click here](#).

Conference Invites

We are again trying to interest certain figures in the establishment to attend the conference. The number of invites to the Chief Medical Officer of England now matches the number of declines - seven in all. It is a shame that Dame Sally cannot manage one attendance at a conference a few hundred metres from her office yet is able to present at a conference in Alberta, Canada two weeks later - ironically entitled Making Connections.

The head of the Medical Research Council has been invited as have the chair and vice-chair of the APPG for ME.

[Read more >>>](#)

Campaigning for Services

In our discussions with several healthcare professionals and PCT administrators it has become clear that it is not the question of simply asking for services for ME patients. The biggest problem lies in medical training and there are very few consultants who are willing to take up ME related posts. If we plainly campaign for services then there is a risk that we only get NICE recommended CBT and GET clinics run by OTs and nurses or, if we are "lucky", with a GP with special interest. Such a situation would not be acceptable for MS or any other neurological illness so why should it be so for ME.

Most neurologists do not believe in ME as a neurological disease so the only way to change the situation is to instigate good quality research and educate clinicians concurrently, such as Invest in ME are doing with our initiative in Norwich. At the moment consultants are afraid of their reputations so we need to show them that ME is a rewarding and interesting area of medicine to be involved in. One way to start changing perceptions is to encourage consultants in various disciplines to attend the IIME conference so that they can see for themselves what real biomedical research is currently discovering.

Ignorance about ME has been allowed to fester in the NHS for a generation, aided by a gullible and manipulated media fronted by buffoons and sound bite healthcare. Our objectives of improving the education of healthcare professionals is the way to confront this ignorance and improve matters for people with ME and their families.

[Read more >>>](#)

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APPG for ME Meetings

Invest in ME were invited to attend APPG meetings by the new chair Annette Brooke MP - an MP whom we believe is intent on improving the situation. Although it hasn't been possible to attend in person (due to personal circumstances in the trustees' families) the charity has nevertheless attempted to play as full role as possible by submitting questions to the APPG and their guests. The questions posed by IiME depend to some extent on having received the agenda within an adequate enough time of the start of the meeting - which hasn't seemed to be the case always.

Our submissions to the APPG are made public beforehand, as best we can, and can be viewed here.

It is to our great disappointment that our questions do not seem to have been put to the group meeting, judging by the minutes which we have been given by supporters, never by the secretariat of the APPG. A similar situation developed with the Forward ME group meetings, to which we were initially invited, but where our input and questions were never discussed or even minuted, let alone answered (for the record they may be seen here).

Our input to the last APPG meeting is here - [click here](#).

At the recent January 2012 meeting the guest was Professor Sir John Savill - head of the Medical Research Council.

From the minutes of the meeting held on 24 January 2012, at which Sir John answered questions about the MRC funding for ME research, it states:

"Ian Swales MP asked whether there is a long term commitment that there will perhaps be somebody who is looking out for this condition. Professor Savill said that there has been a problem in the relationship between researchers and patients in this area and that charities are key in building that interaction. That is what will sustain activity. Ian Swales MP said that Professor Savill had made comment on a positive community. He feels that charities have a key role in maintaining that community and advises an attitude of positivity and not attacking the very people who are trying to help"

The history of MRC funding of ME research has, for a generation, been such that patients have had no other choice but to be angry and question the false science being propagated by establishment organisations and vested interests. Biomedical researchers have not received funding and have been forced to leave the field as the MRC has only favoured behavioural studies.

It needs to be said that patients have a right to criticise studies that they feel are not representing them correctly such as the MRC, Department of Health (DoH), Department of Work and Pensions (DWP) and Scottish Chief Scientist Office funded PACE trial.

Examples -

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If, at the start of the PACE trial, the researchers claimed that patients with an SF36 score of 65 were disabled, and yet by the end of the trial those scoring 60 were being classed as recovered then what are patients supposed to do?

The PACE study was published in the Lancet on 18 February 2011 and there was no mention of conflict of interest by authors White, Chalder and Sharpe.

On 18 February 2012 The Lancet published a letter of clarification regarding the Chalder Fatigue scale used in the PACE trial and at the end of that letter the authors Professors Chalder (TC), Sharpe (MS) and White (PDW) declare their conflict of interest -

"TC has done consultancy work for insurance companies and has received royalties from Sheldon Press and Constable and Robinson. MS has done voluntary and paid consultancy work for government and for legal and insurance companies, and has received royalties from Oxford University Press. PDW has done voluntary and paid consultancy work for the UK Departments of Health and Work and Pensions and Swiss Re (a reinsurance company)."

Why weren't these conflicts of interest declared at the publication of the PACE trial?

The MRC, as funders of the PACE trial, should have taken patients' concerns seriously.

The PACE trial has been shown to be the flawed science that it is - an abomination of a research trial which has needlessly squandered vast resources with no useful outcome for patients or clinicians. Magical medicine! The MRC do need to take responsibility for previous actions and learn from the past mistakes.

Charities need to stop supporting and linking themselves to meaningless behavioural studies - and perhaps patients should look again at the aims and objectives and performance of the charities whom they support.

We hope Sir John's appointment will mark a turning point in MRC direction from the wasteful and negligent path of psychiatry and vested interests to the only path which makes any scientific sense - biomedical research. The recent band of funding for ME research from the MRC is hopefully a sign that a more honest and productive strategy will eventually be found to research ME. One could think of worse ways to progress than to support the IiME proposal for biomedical research in Norwich.

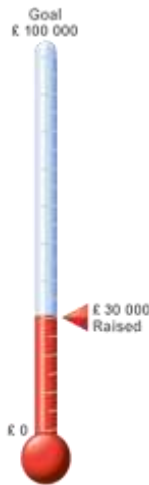
The MRC and Sir John will be judged on actions and performance. We already know how history will judge those vested interests who have, in the past, manipulated the lives of hundreds of thousands of patients and their families.

[Read more >>>](#)

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Let's Do It For ME - Fundraising for Biomedical Research

The campaign to raise funds to support the IiME proposal to establish a UK examination and research facility for ME has now raised more than £30,000.



Some wonderful new initiatives have begun in support of this campaign.

We thank our supporters for this amazing work. There are many talented and innovative people involved in looking for ways to raise funds.

If you want to join this campaign and be part of something really positive then more information can be found on the LDIFME website. Please join us in this wonderful grassroots initiative.

We invite everyone and friends and relatives to get behind this campaign and make as many as possible people aware of the proposal as well as the fund-raising.

Please help us fund biomedical research into ME.

[Read more >>>](#)

Other Fund-Raising Events for Invest in ME

A list of the current EveryClick fundraising initiatives is available using this link - [click here](#).

Thanks to a generous supporter who has donated the first year of funding the subscription we have been able to set up a JustGiving site. The current set of fundraising activities are able to be seen here - [click here](#).

We have also set up a JustTextGiving facility which enables donations to be made by mobile phone. The number to dial for Just Text Giving is **70070** and the text is **IBRF33** followed by an amount to donate - £2 / £5 / £10.

Example - to donate £2 text to **70070** the following text message **IBRF33 £5**

[click here](#)

Other new ways of raising funds at no cost to you include the following -

Invest in ME are now registered with two new schemes Top CashBack and The Recycling Factory.

Top CashBack works in the same way as **Easyfundraising** raising funds for us while

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you shop online. You just sign up and start earning cash back for Invest in ME.

www.topcashback.co.uk/ref/IiME

<http://www.easyfundraising.org.uk/find-a-cause/?q=Invest+in+ME>

The Recycling Factory

Request a freepost envelope and recycle your used ink cartridges, laser toners and mobile phones and earn money for Invest in ME. If you know of a shop or an office that would be willing to collect these items for Invest in ME then The Recycling Factory can provide a box which they collect for free.

<http://www.therecyclingfactory.com/investinme/>

The ways to help us fund biomedical research are on our Help Us page and we shall supplement these when new ideas are generated - [click here](#).

[Read more >>>](#)

Recent Articles

Several recent articles from Margaret Williams can be found in our archived articles page - [click here](#)

More concerns about the current UK Welfare Reform

"A UK Government is democratically elected to look after the best interests of the nation and of its citizens, not to abuse and persecute the sick in favour of foreign corporate profits by imposing the "biopsychosocial model" that is promoted by UK psychiatrists who have vested financial interests in such a "model" because they work for the health insurance industry, whose profits benefit from its use" - [click here](#)

Defending the Indefensible I and II

Professor Simon Wessely attempts to defend what has already been shown to be indefensible, namely his own beliefs about the nature of ME/CFS, including his belief that graded exercise therapy (GET) has "an impeccable safety record" - Margaret Williams explains why this is indefensible - [click here](#) and discusses Wessely's recently published account of his involvement since the late 1980s with what he refers to as Chronic Fatigue Syndrome - [click here](#)

"Grey" Information about ME/CFS

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 - [click here](#)

Statistics and ME

Information about the article "Statistics and ME" by Professor Malcolm Hooper - [click here](#)

[Read more >>>](#)

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Lost Voices

We still have copies of Lost Voices available which is an ideal book for explaining the effects of severe ME to healthcare professionals, the media and the public.

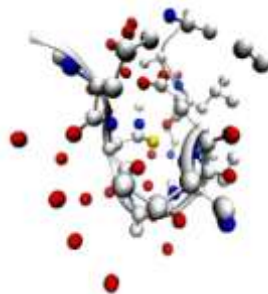


Each UK medical school has a copy and we are happy to help distribute these to doctors and nurses.

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Support the iME proposal to Initiate a UK Examination and Research Facility for ME

<http://www.investinme.org/Research%20-%20ME%20Institute.htm>



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Fundraising for Invest in ME

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

We have wristbands for sale to help raise awareness and fund biomedical research - <http://www.investinme.org/IiME-Wristbands-support.htm>



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.

Use Everyclick whilst surfing the web. INVEST IN ME is listed on **Everyclick** the search engine that helps charity.

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 <http://www.easyfundraising.org.uk/Register/?char=7353> 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.

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Support Invest in ME - support biomedical research