

## Welcome to the Invest in ME Newsletter for August 2010

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## Reflections - 5th IiME International ME/CFS Conference 2010



With fourteen countries represented at the conference the 5th Invest in ME International ME/CFS Conference brought together researchers, clinicians, journalists, patients, support groups and even film crews.

IiME also self-funded places for some media persons and some researchers and offered places to others in order to improve knowledge of ME. Unfortunately the editor of the British Medical Journal, despite numerous emails inviting her to come and assurances that the BMJ would be represented at the conference, nevertheless left it to nine hours before the conference start to inform us that she would not be attending. The fact that the BMJ could not find one person to attend this major conference makes it impossible for the BMJ editorial staff ever to comment on the subject of ME and be taken seriously. They have failed to show themselves as impartial or even scientific and, like many of the establishment organisations, can be seen to have no intention of trying to promote proper science in relation to this disease.

With hindsight the BMJ's tunnel vision was predictable. But there are many more positives from the conference to make up for establishment apathy. One of the attendees at the conference, Dr. Martin Scurr, is a GP and also write a column in the Daily Mail entitled "Ask the Doctor". After the conference Dr. Scurr wrote in his column of 7th June the following -

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"I admit it, I was wrong. For many years, I - like many of my medical colleagues - have blamed ME on psychological or behavioural causes. Then, last month, I attended the 5th (Invest in ME) World Conference on ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome)."

For a doctor and a national newspaper to admit they have been wrong demonstrates the conferences are having an effect. As we have maintained all the while education about the illness is the surest way to defeat the vested interests who have much to lose or who make a living out of the misinformation about ME. The online article by Dr. Scurr is available - [click here](#).

The American Journal of Biochemistry and Biotechnology invited all of the Invest in ME 2010 conference speakers to submit their papers for publication. The first one by Professor Leonard Jason is now available online. We are pleased to see this paper on a revised Canadian Definition published for the wider audience - [click here](#).

The 2010 conference DVD has already been distributed to twenty countries around the world. A new feature for this year's conference DVD was a pre-conference "brainstorming" session with some of the speakers at the conference.

The DVD may be ordered via this link - [click here](#).

The Journal of IiME Issue 4 Vol. 1 was published at the conference and hard copies are still available for sale - £3 plus p&p. It is also available for free online via this link - [click here](#).

Conference Review Page - [click here](#).

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## Invest in ME and WPI UK Studies

The IiME funded WPI UK studies are ongoing and blood draws have been taking place. An IiME cohort of ME patients is included in these studies and we will bring news of the results from the WPI as soon as possible. More blood draws will be taking place in August ([click here](#)).

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## Invest in ME - A Centre of Excellence for ME

At the 2010 conference our intention to discuss the setup of a centre for ME was mentioned. In the last few months we have been discussing the establishment of a facility which would allow correct examination of people using the best guidelines possible (the Canadian Consensus Criteria) and perform translational biomedical research into ME.

We have details of the proposal - [click here](#).

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### Fundraising for Invest in ME

We still have wristbands for sale to help raise awareness and fund biomedical research - [click here](#). We would like to thank our fantastic supporters for the donations, the fund-raising efforts, the E-Bay sales and for the support which you provide and which allow us to continue to provide better education about this illness. Our fund-raising page is here - [click here](#).

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### CMO Reply

We received the following ([click here](#)) reply from the CMO regarding our letter prior to the conference in May ([click here](#)).

The positives from this are -

- that, again, the government recognises ME as a neurological illness and healthcare professionals must recognise it as such
- that the NICE guidelines are only guidelines and do not replace the knowledge and skills of individual health professionals who treat patients
- that individual health professionals may make their own decisions about their patients - and do not have to follow NICE
- that health professionals retain their independence to apply their clinical judgement in deciding which guidelines to use for the diagnosis and treatment of their patients.

The CMO states that, in the UK, people with diagnosed CFS/ME are excluded from donating blood while they are "unwell" and "have symptoms" - an exclusion designed to protect the health of the donor.

Our question on definitions of "recovered" and "feeling well" are ignored.

The UK Blood Services Standing Advisory Committee for Transfusion Transmitted Infections decided it was premature to make any change to the above in regard to the XMRV retrovirus (despite Australia, Canada and New Zealand banning outright blood donations), but that the situation would be closely monitored as new evidence became available from the UK and from Europe. Hopefully the WPI/IIME UK studies may help focus minds.

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### BACME

Invest in ME were recently invited to apply to join BACME - the British Association for Chronic Fatigue Syndrome/ME.

After consideration of this invitation and looking at the constitution of BACME Invest in ME have decided not to apply to join. Our reasons are that to apply to become an executive member one has to join in accordance with the terms of our constitution. One of the

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objectives is to support the delivery of services and to enable services to maintain standards of care in the treatment of CFS/ME as set out in the NICE guidelines.

Invest in ME reject the current NICE guidelines as having little value for treating this illness. This alone mandates us to decline any membership invitation. The organization is chaired by consultant paediatrician Dr Esther Crawley, the medical advisor for AYME and whom we have no faith in to treat ME in the way it needs to be treated and who has been given funding to perform clinical trials using children on LP, a so called training program that encourages participants to be untruthful about their feelings and symptoms. The people running this organisation also, in our opinion, have no role in treating or commenting on people with ME, their treatments or any research which would lead to progress in providing treatments and cures.

We believe the basic foundation of this organisation is flawed and we will not compromise on our view that the only way to treat and cure ME is via a strategy of coordinated biomedical research - not psychiatric therapies and certainly not hyped-up businesses which contain no medical knowledge.

Our statement is available here - [click here](#).

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## Of Interest

Some links which may be of interest -

Inflammation is known to be associated with ME. An interesting article about inflammation is available - [click here](#).

Another article on inflammation and cognitive decline in autoimmune diseases - [click here](#).

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## More XMRV

If one believed that progress would be made on further understanding the causality of ME after the Science magazine publication of the WPI/NCI/CC research (which associated the XMRV retrovirus with ME) then there would have been continual disappointment with subsequent establishment attempts to negate the research and with the behaviour of certain parties in trying to downplay the significance.

Meanwhile the CDC in USA has published its negative XMRV findings whilst another US government agency, the FDA/NIH, has seemingly confirmed the WPI findings. Whilst we await for the FDA/NIH study to be published, there are rumours that efforts have been made to stop the FDA study from being published due to its positive findings. As reported in Nature News on 2 July [<http://www.nature.com/news/2010/100702/full/news.2010.332.html>] "A key study on chronic fatigue syndrome was delayed from publication after officials from the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, learned of a conflicting report published by other government agencies."

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This controversy has created headlines in major science publications and even scientists are now accusing the establishment of a cover-up.

The lay ME/CFS patient community is very knowledgeable about the research being carried out into their disease and is keeping a close eye on these developments. It has also caught the attention of science publications and journalists who have finally shown an interest in the policy based evidence making which is so evident when it comes to ME/CFS research. The story is being followed by Amy Dockser Marcus from The Wall Street Journal [<http://blogs.wsj.com/health/2010/07/01/cdc-teams-xmrp-chronic-fatigue-syndrome-paper-is-out/>]. Amy contacted IiME in June to discuss XMRV and ME. It's also worthwhile looking at Hillary Johnson: Osler's Web (<http://www.oslersweb.com/blog.htm?post=7183515>) and Mindy Kitei, freelance science reporter at <http://www.cfscentral.com>.

The WPI/NCI/CC research in Science from last October may not have resolved causality of ME. However, the genie is out of the bottle. As the saying goes -

All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident.

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## News from the European ME Alliance

Another biomedical research conference is taking place in Dortmund on 25-26th September - organised by our fellow European ME Alliance member Fatigatio. Spread over one and a half days the conference includes Dr Judy Mikovits, Dr Barbara Baumgarten as well as others from Germany and Italy. More details of the conference may be found from Fatigatio's web site at [www.fatigatio.de](http://www.fatigatio.de) or via emailing [info@fatigatio.de](mailto:info@fatigatio.de).

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### Best Wishes

### Invest in ME

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Support Invest in ME - [support biomedical research](#)

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

**easyfundraising**  
.org.uk

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.

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Please help us by using Everyclick whilst surfing the web. INVEST IN ME is listed on **Everyclick** the search engine that helps charity.

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.



### Contacts:

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DVD of 5<sup>th</sup> Invest in ME International ME/CFS Conference 2010

