



# NEWSLETTER

**December 2009**      **Nr. 09/12**

**Welcome to the Invest in ME Newsletter for December 2009**

*published 20/12/2009*

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## **5<sup>th</sup> Invest in ME International ME/CFS Conference 2010**

### **A New Era in ME/CFS Research**



The line up of speakers for the 5<sup>th</sup> Invest in ME International ME/CFS Conference for 2010 is almost complete. Already interest is high coming, as it does, at a time when research into ME has entered a new and hopeful phase.

The conference is entitled A New Era in ME/CFS Research, a title that reflects the momentous changes in ME research caused by the discovery of XMRV and which has really energised ME research. We hope the conference will help further assist in shifting the momentum toward biomedical research.



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Look out for more news of the conference and the conference flyers available soon – ([click here](#)) the conference taking place in Westminster, possibly shortly after a general election in the UK, the conference provides a great opportunity to focus minds on the need for change in research policy toward ME.

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## ME and My MP

The responses are, unfortunately, predictable.

Noteworthy are the comments from Andy Burnham (by way of DoH) - including the sentence "Currently, individuals suffering from CFS/ME are deferred from blood donation until their condition has resolved and they are feeling completely well" - [Click here to see the response in full](#).

We'd like to thank those who have contributed and who take up the spirit of the campaign by focusing politician's minds on need for change in ME.

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## ME AS NOTIFIABLE ILLNESS - Letter TO the UK CMO

Invest in ME received an indifferent response to our letter to the UK Chief Medical Officer ([click here](#)). The response failed even to answer our valid question on whether ME should be made a notifiable illness based on the implications from the XMRV research.

We sent off a letter to the CMO and asked additional questions. For example, Variant Creutzfeldt-Jakob (vCJD) was made a notifiable illness in 1988 by the British government. vCJD is a fatal human neurodegenerative condition, classified as a Transmissible Spongiform Encephalopathy because of characteristic spongy degeneration of the brain and its ability to be transmitted.

The CMO had previously responded that "I do not see any prospect of making myalgic encephalomyelitis a notifiable disease. This classification is only used for a small number of infectious diseases where monitoring is clearly required to sources of infection, and not as a means for collecting statistical information on the prevalence of specific conditions". As the CMO has not bothered to make an epidemiological study of ME and as XMRV seems to be infectious and has consequences for the general public, including blood donation, we thought it worth asking why the difference?

The news that Sir Liam Donaldson is resigning from the post of CMO follows on from the news that the current chief executive of the Medical Research Council, Sir Leszek Borysiewicz, has also announced his resignation. With a likely change of government/government minister also pending then the Department of Health will also be rid of Mrs Anne Keen MP - minister responsible for ME policy.



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We have no wish to denigrate the reputation of Sir Liam Donaldson or anyone else. However, all of these officials share a common trait. They are, in essence, the worst of public servants, be they CMO or minister for health or chief of a supposedly independent research body. For they had the chance to change things, to show leadership, to right injustices and discrimination, to move away from old models of treating ME as a somatoform condition, to make a difference.

As far as ME is concerned all of them have failed.

On the positive side we are now entering a period where there are real opportunities for a change. A new CMO can provide leadership by making ME his personal responsibility, a new CEO for the MRC can force new direction and urgency to the funding of biomedical research into ME, and a new government (of whichever political flavour) can no longer harbour any excuses that "little is known about the cause" of ME.

Those taking the places of the current failed officials will have no excuse for making the wrong decisions regarding ME.

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## **MRC and the Secret File on ME/CFS**

Whatever some may think of the MRC's current, protracted policy toward ME (their current effort, which consists of a panel formed by Professor Stephen Holgate, has taken two years to set up its first workshop) the fact remains that the MRC continues to delay what is urgently required - funding of biomedical research into ME.

Meanwhile a new article from Margaret Williams exposes the secret files which the UK Medical Research Council has locked away from the public for another eighty years.

It is difficult to know why information on an illness, which the Department of Health, the Chief Medical Officer and many official commentators describe as an illness of unknown causality, should have such restrictions placed on any information relating to it.

As Margaret Williams writes -

It is an established fact that the MRC has a secret file on ME that contains records and correspondence since at least 1988, which, coincidentally, is about the time that Simon Wessely began to deny the existence of ME.

To read the full article [click here](#).

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## **PACE Trials**



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Perhaps one of the last vestiges from the old establishment mismanagement of funding for ME research will be published next year by psychiatrists who were given funding from the MRC for research based on flawed diagnostic criteria. Margaret Williams writes in her article on the Pace trials (Can the MRC PACE Trial Be Justified?)-

At the MRC Workshop on CFS/ME held on 19<sup>th</sup> / 20<sup>th</sup> November 2009 at Heythrop Park, Oxfordshire, in his introduction Professor Stephen Holgate effectively said that the reason for the meeting was the need to move forward, **to get away from old models and to use proper science**, and that there was no reason not to change things, a view he had also expressed at the RSM meeting "Medicine and me" on 11<sup>th</sup> July 2009.

[Click here to view the whole article.](#)

The outcome of PACE is predictable (the report will undoubtedly state that CBT is beneficial for people with ME). The fact that proper science, based on biomedical research, has already made the PACE trials redundant and irrelevant is testament to the wasted years of MRC mismanagement.

Unfortunately Professor Holgate has found a strange way to get away from "**old models**" by including known proponents of the psychosocial view of ME to be present on his panel of experts.

Margaret Williams states in another new article - **The role of viruses in ME/CFS: What, if any, will be the effect of the discovery linking XMRV to ME/CFS on the MRC PACE Trial?** - ([click here](#))

Could it be said that the Wessely School has created a similar environment in the UK and that the MRC PACE Trial is part of that constructed environment, just as the NICE Clinical Guideline and the actions of NICE which resulted in the failure of the Judicial Review were also part of it?

This constructed environment will eventually be brought down by good science - "proper science" - and those who established it will eventually be judged by history, if not brought to account before by the judicial system.

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## NICE - the Statements That Weren't Seen

As a postscript to the NICE Judicial Review Margaret Williams has written an article on the statements from those opposing the NICE guidelines, but which were not previously publicised ([Statements of Concern about CBT/GET provided for the High Court Judicial Review of February 2009 - click here](#)).



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Despite these damning statements against NICE, for the judge at the judicial review it was not the content of the guidelines that mattered but the procedure used in creating it. NICE were therefore at liberty to have written almost anything as long as it could prove that correct procedures were followed. A new opportunity for change comes in the New Year as the existing guidelines are to be reviewed.

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## A Chance to Help Biomedical Research into ME

Maybe a new chief executive or a new government will bring the change in policies required. Maybe the XMRV research will make the MRC policies redundant. But we could wait forever for the MRC to acknowledge the obvious and for Professor Holgate to convince the MRC to fund biomedical research - "proper science". Or we can do what we can ourselves.

Invest in ME have decided to work with another charity, ME Solutions, to begin a fund-raising campaign for research to be performed by Dr Jonathan Kerr and Dr Amolak Bansal of Epsom and St Helier hospital (see our press release detailing the research - [click here](#)).

Dr Kerr has been starved of funding from the UK Medical Research Council (who has used the nonsensical excuse that there have been no high-quality applications for biomedical research).

Dr Kerr has been working with Dr Mikovits from WPI and they have even been awarded funding from USA's NIH. The fact that Dr Kerr has to look to the USA for funding to perform research shames the UK government and the establishment organisations such as the MRC.

Invest in ME wish to help Dr. Kerr's continued work and further the research around XMRV and immune system dysfunction.

We knew there would be concerns around Dr Bansal's connection with the CNCC clinic at the St Helier hospital. Some of the concern is understandable. Invest in ME have also been critical of the government's CNCC clinics as not being set up correctly to serve patients with myalgic encephalomyelitis. We were also concerned that some of the information about ME on the Epsom and St. Helier website was incorrect and we have suggested to Dr Bansal, via ME Solutions, that it be removed or corrected.

However, the same department web site also states that - "The main research interests of the department include NK cells and infertility, allergy, immunodeficiency and the chronic fatigue syndrome." and "NK cell activation and cytotoxicity are routinely performed within the department of Immunology at St Helier Hospital."

So Invest in ME discussed this with Dr Kerr and ME Solutions. Dr Kerr's respect for Dr Bansal's expertise in immunology convinced us to give our support to this exciting new project. Dr Kerr has already collaborated with Dr Bansal on ME/CFS research. It is worthwhile looking at the actual research proposed. The important item is the research to be performed and in this case we need to look to the future.



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The title of the research project is "The role of XMRV in modulation of NK cell cytotoxicity and NK cell gene abnormalities in ME/CFS patients"

The research is distinct in that it will relate the presence of XMRV in NK cells with other CFS-associated abnormalities previously demonstrated in NK cells. XMRV has been cultured from T, B and NK cells, but primarily targets NK cells. NK cell dysfunction has previously been found to be abnormal in ME/CFS, despite their numbers often being largely unaffected. Defects in the innate immune system are thought to play a key role in the pathogenesis of ME/CFS and these abnormalities may leave individuals susceptible to XMRV infection. This study will relate the presence of XMRV in NK cells with ME/CFS-associated abnormalities previously demonstrated in NK cells and ME/CFS-associated gene abnormalities.

The research project also proposes to select patients according to the Canadian criteria and the Fukuda criteria - thus standardising on the same criteria being used by the WPI in its research. We believe this will help in setting a baseline for future research. If one wishes to have research using patient samples diagnosed according to the Canadian Criteria then one has to start somewhere and we fully trust Dr Kerr in his commitment.

For this research project Invest in ME and ME Solutions will be able to make joint grant applications - the reasoning being that two ME charities working together to fund-raise will make it a more attractive proposition for grant-giving bodies.

We would expect the majority of any funding for the project to come from these grant applications but often a funding body wishes to see some funding secured separately.

We welcome support and contributions from organisations that have funds for biomedical research and who wish to contribute to XMRV research. We also welcome support from individuals who are able and willing to support one of the key ME researchers in the world today.

Invest in ME will be contributing to this project, as best we can, using our Biomedical Research Fund. Our interests are in getting funding for biomedical research into ME and for Dr Kerr to continue to perform ME research and cooperation with Dr Mikovits and the extraordinary WPI team.

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## Research Papers

A new research paper by Dr Jonathan Kerr was recently published. "Antibody to parvovirus B19 non-structural protein is associated with chronic arthralgia in patients with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME)" - details [are here](#).

Dr John Chia also recently published research - "**Acute enterovirus infection followed by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and viral persistence**" - details [are here](#).



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## Lost Voices

Invest in ME are pleased to announce that a grant application to print a new batch of Lost Voices has been successful. This will allow us again to make this wonderful book available. Natalie will hopefully be making some small changes to the second edition and we may also have some other information added. Already the book has had a great effect in many countries and we look forward to being able to use the book and the experiences of the contributors to educate the public, politicians, the media and healthcare staff of the true nature of ME.

Lost Voices can be ordered [via this link](#).

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## *...and finally - for Christmas*

If you need ideas at Christmas to help support ME then we have a page with ideas - [click here](#).

If you are still thinking of a Christmas or New Year present to give why not try giving a copy of Osler's Web by Hillary Johnson? The book has been reprinted and [is available here](#).

As we enter a new year, with another new conference, there are grounds to hope for people with ME and their families. In 2010 the Whittemore-Peterson will be formally opened. We hope our conference will hear of new research and more findings which will benefit healthcare professionals in understanding ME. We are finally witnessing change, albeit forced on to reluctant establishment organisations. We hope, with our colleagues at the [European ME Alliance](#), that 2010 will be a special year.

Happy Christmas to all,

Invest in ME

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