

Welcome to the Invest in ME Newsletter for February 2010

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The 5th Invest in ME International ME/CFS Conference 2010

A New Era in ME/CFS Research



The agenda for the 5th International ME/CFS Conference on 24th May 2010 is being finalised and will be available soon on our [conference web site](#).

Delegates from USA, Australia, New Zealand, Scandinavia and Europe have already registered and, with a block of seats reserved for professionals it is advisable to book early. We hope to have more news of media coverage and some useful information for delegates.

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Since after the 2007 conference we decided to reserve a permanent place in future conferences for the Whittemore-Peterson Institute to present as it was clear to us that the WPI was an organisation which seemed to have the vision to pursue a co-ordinated strategy of biomedical research into ME. In 2007 and 2009 Annette Whittemore came to London to describe the new Whittemore-Peterson Institute being created in Nevada and Dr Dan Peterson presented on his approach to diagnosis and treatment based on his many years of experience of seeing this group of patients. Together they presented the ambitious plans for the WP Institute for researching ME/CFS.

In 2008 and 2009 we welcomed the WPI's Research Director, **Dr. Judy Mikovits**, to talk about the WPI's future research. The XMRV research published last year has energised ME research and provided more hope for people with ME and their families than all of the so-called strategies which the USA CDC and UK Medical Research Council have produced in the last twenty years.

This year we welcome Dr Mikovits again to provide an update on the XMRV research and we hope there will be more data available for publication then. The WPI formally opens in the Autumn this year.

Dr. Paul Cheney MD, PhD has been a pioneer in trying to uncover the myriad of symptoms experienced by ME/CFS patients. He was a clinician working alongside with Dr Peterson at the time of the Incline Village outbreak in Nevada, so well described by Hillary Johnson in Osler's Web. He has carried on seeing patients with ME/CFS and is pioneering with novel treatments such as those involving stem cells.

Professor Brigitte Huber PhD, is a researcher at Tufts University in Boston USA. Her expertise is in genetics and immunology and her ultimate goal is to find new insights into the mechanisms that lead to autoimmunity. Currently she is involved in a CFS research project which is looking at the molecular and functional analysis of a human endogenous retrovirus, HERV-K18, which encodes a superantigen.

Dr Nancy Klimas MD has been a leader in the field of ME/CFS research for many years and recently opened a model clinic for CFS patients in Miami with the aim to treat patients as well as train doctors. Dr Klimas has published over a 130 peer reviewed scientific papers. Dr Klimas is a member of the federal CFS Advisory Committee (CFSAC) and former President and current Board Member of the International Association of CFS/ME (IACFS/ME).

Dr. Jonathan Kerr MD, PhD is now the principal investigator in a programme of research in ME/CFS. This involves development of a diagnostic test using mass spectrometry, analysis of human and viral gene expression in the white blood cells, and clinical trials of immunomodulatory drugs. He has recently published research identifying distinct subtypes in patients with ME/CFS.

A lot of the focus recently has been on XMRV but we haven't forgotten the more traditional research into ME. Enteroviruses cause acute respiratory and gastrointestinal infections, with well documented tropism for the central nervous system, heart and muscles.

Professor Nora Chapman PhD studies persistent coxsackie infections in murine models of chronic myocarditis and dilated cardiomyopathy. She and her associates have demonstrated

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that selection of defective enterovirus in heart and other tissues leads to persistent infections despite active antiviral immune responses.

Dr John Chia MD will follow on from Professor Chapman in discussing his research with enteroviruses. He has performed research validating the work the late Dr John Richardson was performing for many years regarding enteroviruses. Dr Chia's analysis of 200 patients identified a number of potentially treatable infectious aetiologies, enteroviruses being causative possibly in more than half of the patients. Other infections which have been linked to ME/CFS are Epstein-Barr virus, cytomegalovirus(CMV), parvovirus B19, Brucella, Toxoplasma, Coxiella Burnetti, Ross river virus and Chlamydia pneumoniae.

Conference News

We are pleased to announce that **Professor Leonard Jason PhD** will also be speaking at the Invest in ME conference. Dr Jason gave an impressive presentation at our 2008 conference ([on dvd here](#)) and has vast experience of research into ME. Professor Jason will have a new paper on revision of the Canadian criteria in his talk which will be - How Case Definitions Can Stigmatize: Implications for Epidemiology, Aetiology, and Pathophysiology. This an appropriate time for Professor Jason to address these issues.

The WPI staff have been enormously busy since before and after the XMRV announcement was made in Science magazine last year and the Institute has its opening in the autumn. We are hopeful that the President, Annette Whittemore, will be able to complement the WPI presence at the conference.

The conference for 2010 is entitled A New Era in ME/CFS research with the theme Education of Healthcare Professionals. But how do we get that message out of the need for healthcare professionals to become aware of the new research into ME/CFS?

To find new ways of doing this we have invited the General Medical Council to the conference.

It is an urgent requirement that medical training should reflect the results of biomedical research, even if it is being funded mainly by private means. The new advances in ME/CFS research need to be reflected in the curriculum of medical students. So we hope the GMC will be able to help us help them in changing the system.

Student speaker - we are hoping to enable time for a student speaker to present at the conference. A new slot is being made to implement an old idea. One of IiME's aims is to sponsor PhDs so that proper research into ME/CFS can be carried out. So we'll start here.

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Invest in ME have extended invitations to other organisations to attend the conference in order to provide more information about their work which we believe will be of use for people with ME and their families. More news on this later.

ME/CFS Support Groups

We would like to ask all ME/CFS support groups to support the conference and to try to get as many local healthcare staff as possible to come along. The conference provides a focal point for ME support groups and healthcare professionals to cooperate. This is vitally important if we are to ensure that healthcare services accurately reflect the knowledge of the illness from the biomedical research which has taken place. The conference carries CPD-accreditation, as in previous years, so it counts towards any healthcare professional's training.

Our discounted tickets for healthcare professionals, via the **Sponsor a GP** scheme, are available and cost nothing to support groups.

We would appreciate any help we can get in distributing copies of our conference flyer and poster to local GPs/consultants or in placing them in hospital waiting areas so that more people can become aware of this important conference. IiME will send out flyers/posters or other details to any groups who wish to include them with newsletters to members.

Contact us if you would like us to send you anything.

[Click here](#) for downloading our conference documents.

Disorders in the inflammatory and oxidative and nitrosative stress pathways and Cardiovascular Disorders



Just a reminder that we published the paper by Professors Frank Twisk and Michael Maes regarding this topic - [click here](#).

XMRV Research - Look to the End

Since Science magazine published the XMRV research by the WPI, National Cancer Institute and the Cleveland Clinic there have been several attempts to cast doubt on the quality of that research. It seems a strange way to conduct science where the quality of the research and the methods employed to perform the research are seemingly thought of as having been carried out by a couple of amateur scientists and published by a school magazine.

It needs to be re-stated that the original XMRV research was carried out by organisations which are professional and expert in their processes. It also needs to be re-stated that the

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work was a culmination of years of work and underwent a rigorous six month peer review process by Science magazine before it was published.

Compare this with the recent research using different methodologies and patient cohorts which now have been carried out by Erlwein et al., Imperial College, published online in Plos One

[<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0008519>] and, more recently, by a new study (published 15 February 2010) in the online journal Retrovirology by Harriet C T Groom et al. "Absence of xenotropic murine leukaemia virus-related virus in UK patients with chronic fatigue syndrome" *Retrovirology* 2010, 7:10doi:10.1186/1742-4690-7-10 [<http://www.retrovirology.com/content/7/1/10/abstract>].

Erlwein et al. found no XMRV by nested PCR (0/186) in their samples and the research by Groom et al. has not identified XMRV DNA in any samples either by PCR (0/299).

These two studies were not replication studies of the original one published in Science magazine and patients were told to expect negative results by Drs. Klimas and Bell as the first studies are being published.

These first studies used different methods when trying to validate their test to detect XMRV in blood samples from CFS patients.

We are reminded of Dr Chia's words in his entry in Lost Voices which was published before the discovery of XMRV in CFS. Dr Chia writes -

"I realize that many of the assumptions that were made about this illness during the past two decades were erroneous. The discrepant results from different laboratories were probably due to differences in the handling of blood samples, and the sensitivity of the tests used to document the presence of virus in the tissue of ME/CFS patients"

and in relation to similar problems of early HIV research

"The problem was solved after this wise researcher sent his workers to another laboratory to learn how to do the test."

This is what should be done with the XMRV research in order to stop wasting precious time and money. Collaboration and cooperation is the key. We should learn from past mistakes.

We are sure all this will be well discussed at the IIME May conference. The existence of the XMRV is not questioned and there is a lot of interest in studying this new retrovirus.

The WPI comments on these two studies can be seen here
http://wpinstitute.org/news/news_current.html -

Expert opinion discussing this latest study by a virology professor can be found here -

<http://www.virology.ws/2010/02/15/xmrw-not-found-in-170-additional-uk-chronic-fatigue-syndrome->

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patients/?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+VirologyBlog+%28virology+blog%29&utm_content=Google+Reader

In order to get an idea how several experts discuss XMRV and CFS there is a free 3-week trial to join the Faculty of 1000 Biology and gain access to expert opinion - see <http://f1000biology.com/guardpages/evaluation/1166366//article/article.asp%253Fid%253D1166366%2526view%253D%2526style%253D>

IiME's opinion is that any replication studies need to be using exactly the same method as used by WPI, NCI and Cleveland and in close collaboration with the original researchers to benefit patients sooner rather than later.

The true replication studies are yet to come. These are early days still.

Fundraising for Invest in ME

On the 21st February 2010 Gráinne Devery is running the Wokingham half marathon for Invest in ME. Gráinne has set up a page on our Everyclick site - [click here](#). If you live around Wokingham, or know anybody else who does, then please help raise awareness by getting people interested to help Gráinne along.

Helen Milstein is again bravely defying the elements and entering the water again. Her fund-raising page for IiME is entitled MAD WOMAN PLUNGES INTO ICE-COLD WATER!!! - [click here](#) - and with the recent UK weather we wouldn't disagree. Helen did this last year to raise money for biomedical research and the amount raised was added to our Biomedical Research Fund ([click here](#)) - one of whose aims is to fund Dr Kerr's research ([click here](#)).

Also just started on a fund-raising venture is Amy Hanson [click here](#). Amy is currently looking for ideas for her page (marathon running and freezing water swimming have been taken) so if anyone has ideas please pass them on.

We would like to thank Barbara Milson for her event last year which raised money for IiME at the Caterham Dene Fete. We have a picture, along with other recent events, on our fund-raising page - [click here](#).

Magical Medicine

We recently added articles from Margaret Williams to the web site.

- [Secret Files of the Medical Research Council](#)
- [Can the MRC PACE Trial BE Justified?](#)
- [More evidence of inflammation in ME/CFS](#)
- [Interstitial cystitis and Chronic Fatigue Syndrome](#)
- [Documented Involvement of Viruses in ME/CFS](#)

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Some of these articles were part of a larger document which was being created, and which have now been published under the title - **Magical Medicine: How to Make a Disease Disappear.**

This 442 page report has been produced to show the failings of the Medical Research Council and specifically the PACE trials.

The report addresses the background to the MRC "PACE" Trial on "CFS/ME", the biomedical evidence that disproves the assumptions of the MRC trial Principal Investigators, the many extremely disturbing issues surrounding the PACE Trial, and illustrations from the Manuals used in the trial.

The document contains the background to consideration of and quotations from the Manuals for the Medical Research Council's PACE Trial of behavioural interventions for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis together with evidence that such interventions are unlikely to be effective and may even be contra-indicated.

The failings of the Medical Research Council, past and present, have culminated in an official complaint being made by Professor Malcolm Hooper.

The links to the Magical Medicine document, and to the formal complaint to the Minister of State responsible for the Medical Research Council, which Professor Malcolm Hooper has submitted, may be found here - [click here](#).

Magical Medicine in Action

In the light of this latest epic piece of Hooper/Williams research it is interesting to reflect on the comments of Professor Stephen Holgate of the Medical Research Council (and head of the current MRC panel looking at ME research) in a Times online article on 25 January 2010

[http://www.timesonline.co.uk/tol/life_and_style/health/features/article6998742.ece]

"...As a clinician who sees patients with this group of diseases I recognise there's a real thing here, it's not all psychiatric or psychological. Unquestionably in some of these patients there are abnormalities and biochemical changes in the brain, the central nervous system, the spinal cord or the muscles. My personal view is that we're not dealing with a single condition."

Even to a lay observer this might then mean there is something wrong in the current process of diagnosis. For the representative of the MRC (an organisation that has consistently maintained that there is a lack of high quality research applications into ME) such an admission that the MRC are not dealing with a "single condition" should obviously make it mandatory that his panel establish a correct set of diagnostic criteria for ME as the basis of future research.

Yet nothing has been decided in this area during the two years it has taken to get one meeting arranged by that panel - and time slips by.

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This should surely also ring alarm bells that the MRC is maintaining a false strategy by continuing to mix the psychosocial and the biomedical factions together which will fudge research and continue to waste lives.

We have serious doubts about the likelihood of the MRC or their panel ever progressing to the point whereby they fund biomedical research - and the Magical Medicine clearly shows this.

So let's test the workings of the MRC panel now.

Invest in ME have written to Professor Holgate and invited him to recommend funding of Dr Kerr's recent XMRV proposal ([click here](#)). Dr Kerr is a world-class researcher on ME and, although he does hold a place on the latest MRC panel, we wonder if that panel will be allowed to decide whether this is of high enough quality.

We have also invited him to standardise on usage of the Canadian Consensus criteria for selecting patients for all future research into ME.

As we have stated previously the issue of research into ME would be relatively simple to resolve if there were no vested interests involved. The MRC are chiefly responsible for this, allowing an environment to exist where suspect research is funded without proper controls and high-quality research is stunted.

Such a situation is described by Pallab Ghosh, science correspondent, BBC News, 2 February, 2010 [<http://news.bbc.co.uk/1/hi/sci/tech/8490291.stm>] in which he writes about biased peer reviewing regarding stem cell research which sounds so similar to the plight of ME researchers.

The landmark research by the WPI, National Cancer Institute and the Cleveland Clinic which led to their XMRV and CFS research paper being published in Science magazine, succeeded after six months of rigorous peer reviewing. Yet a paper by Erlwin et al., published in an online Journal PloS ONE, had but a few days of peer reviewing before being widely quoted in the British press in attempts to refute the WPI findings.

As an example Pallab Ghosh writes -

"Stem cell experts say they believe a small group of scientists is effectively vetoing high quality science from publication in journals.

In some cases they say it might be done to deliberately stifle research that is in competition with their own."

This seems to have been the case with the MRC and biomedical ME researchers for the past 20 years.

Magical Medicine!

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New Head of CFS Research at CDC

Across the Atlantic that other inhibitor of progress into ME/CFS - the Centres for Disease Control - has removed Dr William Reeves from the post of Head of CFS Research. This is welcome news for the ME community and the hope is there that change is on the way.

In our last newsletter ([click here](#)) we mentioned that now is the time for change with an opportunity for far-reaching reform of the way research into ME is funded and how government organisations perceive ME.

Yet for some any change will come too late.

Lynn Gilderdale

The tragic story of Lynn Gilderdale's death and the trial of her mother has made ME a story which has now appeared on the front pages of newspapers and as the main story of television news programs. Invest in ME have refrained from commenting on this case. There are few more words necessary to describe the tragedy and this case is personal and evokes differing views.

This case has itself been added to the debate on assisted suicide rather than posing the single, simple question which should have been at the front of the coverage by everyone discussing or reporting the case - why did it ever come to the situation where a mother has to participate in the death of her daughter?

The failings of the government, the Chief Medical Officer and certainly the Medical Research Council ought, perhaps, to have been on trial - or at least examined by the media. Hopefully Professor Hooper's official complaint to the Minister responsible for the MRC may bring forth some examination of a generation of time-wasting, pseudo-science and obfuscation by the establishment.

If patients such as Lynn had had a diagnosis of diabetes or heart disease there would have been access to all kinds of support and specialist services based on biomedical understanding of the illness and by staff appropriately qualified to help. Due to lack of acceptance of ME as a neurological illness, and the consequent cascade effect of no funding for proper research, then no services have been developed for severely affected pwme. Still it doesn't stop some commentators speculating whether ME exists at all as they continue the myth of the 'chronic fatiguing' illness ME.

Invest in ME responded to an editorial article in the British Medical Journal about the case. Our response on the BMJ Rapid Responses web site was not published - so we have published it here - [click here](#).

The case of Lynn Gilderdale is reason enough to demonstrate why one cannot marry the psychosocial view of ME with the biological view of the illness and why Professor Holgate's strategy of doing so is seriously flawed.

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The current media interest has been around Lynn but unfortunately there are many others like Lynn lying in their homes being cared for 24 hours a day, not having any medical attention for years. And other cases where children are being forced to exercise and change behaviour to "overcome" their ME. The policies of the MRC for the last generation and the continuing tardiness with which they treat the urgent need for biomedical research is appalling.

E-petition Response from the Prime Minister's Office

A recent petition initiated by Dave Loomes requested that a public inquiry be set up to investigate the vested interests which have so manipulated the establishment policies around ME - see here <http://www.number10.gov.uk/Page22366>

The reply is staggering in its crass refusal to even analyse fully the question posed. The government classifies the illness as neurological (G93.3) and yet their reply states that the classification of ME is confusing and controversial since there are five different World Health Organisation categories that could be chosen by a doctor to describe the illness.

One can easily identify where the information for this reply comes from. This reply only goes to reinforce the reasons why the MRC will never fund biomedical research into ME.

The last paragraph of the reply reflects on Professor Peter White's presentation at the Royal Society of Medicine CFS/ME conference held in 2008 where he spoke about the classification needing "sorting out".

Patients have no problem with ME ICD10 G93.3 classification. It is quite clear what it means and the reply from the government shows exactly the reasons why Lynn Gilderdale and others like her are left to suffer without any hope of proper treatments.

Lost Voices - New Edition

The order for a new edition of Lost Voices has been made.

The second edition has been updated to include details of the latest research and an additional Voice - Christine Hunter, of the Alison Hunter Memorial Foundation, has allowed Alison Hunter's story to be included. Lost Voices has articles from Annette Whittemore, Dr John Chia and others as well as the stories from people with ME and their families.

Invest in ME will use the book to further



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awareness of this illness in the run-up to ME Awareness Month in May and to counter the prejudiced denial of ME - as an *'aberrant belief'* rather than a devastating physical illness.

We also still have the Sponsor a Book scheme whereby we will send a book to the healthcare (or other) person whom you choose with a message. [More details here.](#)



News from the European ME Alliance

A new member was added to the European ME Alliance. Switzerland has become the latest country to be represented by the Alliance with Verein CFS Schweiz joining. More details are here - [click here](#). This brings to nine the number of countries currently represented.

The EMEA groups are so far organising two conferences this year.

Apart from the IIME conference in London our German colleagues are organising a biomedical research conference in Dortmund, Germany, on 24th September.

The Alliance hopes to have more news of other events planned over the next few months.

Best Wishes

Invest in ME

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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.



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