

Welcome to the Invest in ME Newsletter for March 2011

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IN THIS ISSUE

**6th IiME International ME Conference -
The PACE Busters**

Pre-Conference Evening

Australian Symposium

PACE Trials and MRC Funding

NICE Response

NIH Knowledge Committee Workshop

ME Awareness Month

The PACE BUSTERS - IIMEC6

The 6th Invest in ME International ME/CFS Conference 2011

The Way Forward for ME - A Case for Clinical Trials

Conference IIMEC6 focuses on the need for clinical trials for ME.

Clinical trials are biomedical research studies aimed at determining the efficacy, safety levels, and possible side-effects of new medications and therapies. The majority of clinical trials involve testing new medications designed to treat many types of conditions, ranging from auto-immune and blood diseases to cancer. In the case of new medications, the trials are jointly run by pharmaceutical companies, which are responsible of designing the new drugs, and hospitals or health centres, which administer them to patients.



It is interesting to note that Dr Jonathan Kerr was presenting on starting clinical trials at our first 2006 conference. His first choice of drug at that time was interferon-b as it was widely useable with immune modulatory as well as antiviral properties. A drug company had already promised the drug but of course we now know that Dr Kerr didn't get any funding to administer the trials. We are left wondering were we would have been had Dr Kerr been given the funding to do all the clinical trials he was planning on doing.

Conference Agenda

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

Invest in ME Newsletter for March 2011

Mrs Annette Whittemore, President of the Whittemore-Peterson Institute, will be opening the conference. It is appropriate that an organisation that has its roots in helping patients, and which is furthering the idea of biomedical translational research, should open the conference.

Our permanent conference slot for the WPI is again filled this year by Research Director Dr Judy Mikovits who will be presenting the latest on XMRV research.

One of the world's most experienced, and certainly Europe's most experienced ME researcher is Professor Kenny De Meirleir and we welcome Professor De Meirleir back for the third time to an IiME conference.

Unfortunately Dr Jose Montoya has had to cancel his planned visit to the conference for reasons beyond his control. Dr Montoya really wanted to attend the meeting and is disappointed to miss it. We hope we can arrange another opportunity in the future. We welcome Dr Andreas Kogelnik to the conference. Dr Kogelnik worked with Dr. Montoya on a placebo controlled double blind antiviral study to test the efficacy of valganciclovir on a subset of ME (CFS) patients (J Clin Virol. 2006 Dec;37). He is the founding director of the Open Medicine Institute, a collaborative, community- based translational research institute dedicated to personalized medicine.

Dr David Bell has enormous experience and a special perspective on ME. He was the paediatrician in the middle of an ME (CFS) outbreak in the rural village of Lyndonville where 214 residents among them 46 children became ill with a mystery disease. Dr Bell has followed his patients ever since still looking for the cause of his patients' ill health.

Professor Olav Mella and Dr Øystein Fluge are cancer researchers from Bergen University in Norway and they have been trialling Rituximab for ME patients with promising results.

Dr John Chia returns to cover the role of enteroviruses in ME. Dr Chia is continuing his enteroviral research looking at the pathogenicity of the viruses he and his team have found. Dr Chia sees and treats a great number of ME patients.

Dr James Baraniuk is currently associate professor at the Department of Medicine at Georgetown university in Washington and will be presenting on cerebrospinal markers in ME.

The University of East Anglia's research park is the focus of IiME's attempt to initiate an examination and research facility for ME and is well equipped to perform state of the art research into ME. We are delighted to welcome Professors Tom Wileman and Simon Carding to tell us what could be done to advance research into ME in the UK.

Dr Wilfried Bieger is a docent of Medicine in private practice in Munich, performing a study in co- operation with a researcher from Heidelberg University to test German ME patients for XMRV. The results of this study will be presented at the Invest in ME conference.

We hope the conference will help further assist in shifting the momentum toward biomedical research. Keep up to date with news of the conference [via this link](#) - a conference flyer and other documents are available here - [click here](#).

Invest in ME Newsletter for March 2011

Conference Invites

We have again tried to interest certain figures in the establishment in order to better inform them of the status but also the possibilities with proper research into ME.

BMJ

We are happy to announce that the BMJ have agreed to be represented at the conference and participate in panel discussions.

CMO

As many know we again invited the Chief Medical Officer. Six conferences....six invitations....six refusals. What should it take to get England's Chief Medical Officer to attend an Invest in ME International ME/CFS Conferences which have some of the foremost experts on ME presenting biomedical research?

IiME thought that, with a change of occupancy at Richmond House, Whitehall, there might be an opportunity to divorce ourselves from the inactivity, apathy and disregard for human suffering which has characterised the last decade comprehensively performed by the previous CMO. Not so! The following reply came from our invitation to the CMO to attend the conference -

Thank you for inviting Dame Sally Davies to attend your annual conference on ME/CFS to be held on Friday 27 May 2011. Unfortunately, Dame Sally has a prior commitment on the date given and I'm afraid therefore it is not possible to accept your kind invitation on this occasion. Please accept our apologies for this.

IiME followed up with a request to send a representative from the CMO. The even more terse response confirms that apathy and lack of any pro-activity is alive and well and ignorance will be a continuing pillar of the establishment view of ME -

Thank you for your further email. I regret the Chief Medical Officer has no representative to nominate at this time.

See <http://www.investinme.org/IIME%20Campaigning-CMO-Conference%202011.htm>

Despite having to be forced into introducing a lifetime blood ban for people with ME there seems to be no compulsion to learn, no eagerness to deal with, no urgency to resolve from the CMO's office.

We leave the reader to decide if we should have expected more.

Attending conferences is not alien to Dame Sally in her new role as CMO ([click here](#) and [here](#)) and we wonder how much notice of an invitation to speak she would have received for those events (surely not more than the eight months given by IiME every year since 2005).

The conference venue of Birdcage Walk is about 200 metres from Richmond House. The invitation remains open.

Invest in ME Newsletter for March 2011

Pre-Conference Evening presentation

As part of our conference this year we are again organising a pre-conference dinner. This year we invite back Hillary Johnson, author of Osler's Web. Hillary presented in our pre-conference presentation of 2009 when she spoke of the CDC and its influence worldwide [[available on the 2009 DVD here](#)].

This year Dr. Ian Gibson will be joining Hillary and the theme of the presentations will be Science, Politics....and ME and will look at the reasons for lack of funding and performing of biomedical research into ME.



Dr Gibson is a scientist, politician and academic and is uniquely qualified to present on this topic. He has been a strong advocate of science in the UK and has been assisting IiME in our attempts to get a research and examination facility set up in Norfolk, UK.

IiME have, as with the actual conference day, subsidised the cost of the event to allow it to be within the reach of as many as possible. However, places are limited and this event is already fully booked but we are holding a reserve list and there may be options for attending.

Please [see this link](#) for further details.

Australian Symposium

The Australian symposium organised by the Bond University and The Alison Hunter Memorial Foundation published the abstracts and a communiqué from the event ([click here](#)).

Researchers had gathered for the two day symposium to exchange ideas and plan for the future and Invest in ME sponsored a virologist from UEA with no previous ME experience to participate. This was in connection with our proposal to set up an examination and research facility in Norwich Research Park.

The symposium involved researchers who perform research relevant to ME in other diseases and experienced ME researchers to encourage dialogue and exchange of ideas. It is especially welcoming that the participants of the symposium agreed that the correct name to be used for this disease is myalgic encephalomyelitis and the diagnostic guidelines that should be adopted internationally are the Canadian Consensus Guidelines. Invest in ME and the European ME Alliance have been promoting this approach for some while.

Invest in ME Newsletter for March 2011

PACE Trials and MRC Funding

Two years ago we wrote -

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 19th / 20th 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 11th July 2009.

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

We wrote then that -

"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."

And so it happened.

The PACE trials were published and it is apparent that they have served no useful purpose, lacked scientific rigour and are the result of biased research. Also, of course, almost £5 million has now been wasted instead of being used for biomedical research which could have really made a difference to hundreds of thousands of people's lives.

As we commented in December 2009 - "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."

The architects of the PACE trials are present in the latest MRC panel. Despite the sham of the PACE Trials this mismatch of different views on the MRC panel continues.

The MRC recently announced its intention to allocate "up to £1.5 million" for ME research - see http://www.mrc.ac.uk/Ourresearch/ResearchInitiatives/CFSME/index.htm#P121_7379.

Invest in ME Newsletter for March 2011

IIME's response initial response [is here](#) and our response to the Lancet (who published the paper) [is here](#).

One of the authors of the PACE trial, Professor Michael Sharpe, has recently moved to Oxford University, Psychological Medicine Research. The research areas of this unit include studies into the nature and management of symptoms unexplained by organic disease, studies of the management of depression in cancer patients and a trial of treatments for chronic fatigue syndrome (the now published PACE trial). The MRC research strategy of looking at symptoms such as pain and fatigue and sleep dysfunction in ME/CFS seem to be tailor made to allow the psychiatrists to continue to dominate MRC policy.

And so our statement about the MRC funding and its priorities seems correct as we can now expect the MRC panel to allow further time to be wasted by looking at these symptoms and allow psychiatrists to continue to control the research debate.

It should be clear now that it was a flawed approach to incorporate in the MRC expert panel those who attempt to portray ME as a behavioural illness. It is impossible to bring together the biological (based on good science) and the psychological faction (based on vested interests and bogus science), without risking the lives of thousands of patients. And we continue to wonder if other organisations and individuals who participate in the MRC panel in search of funding will be forced into performing watered-down research similar to the colossal failures of the PACE and FINE trials.

Why retain this line instead of joining with those who say we must cooperate at any cost, whatever the differences?

Why not remain silent as others do when something as damaging and irrelevant as the PACE trials are published, or who are quick to join the establishment propaganda who maintain that the WPI (and by association the National Cancer Institute and the Cleveland Clinic and the investigators behind Science magazine) can't perform biomedical research without contamination?

IIME have been helping a number of severely ill ME patients over the years and our recent experience continues to show that these patients are truly neglected due to all relevant agencies from social services to GPs, legal advisers, charity workers and family members viewing ME as a mental health problem rather than a physical illness that it is. Especially in London the advice given to these agencies seems to be not to give any practical help to patients diagnosed with ME as it might stop them trying to do things for themselves. It takes a lot of time and energy trying to resolve years of ignorance, neglect and malpractice which has led to total loss of confidence and trust in the system. We can only hope that our efforts are helping to change a few of those minds working for these public agencies so that other patients in the future will get proper help before things spiral out of control.

For example, a house/bed bound patient was offered only a bus pass and food coupons when they asked for help from social services. The patient had not had a hot meal for years and was living off the odd food parcel sent by fellow patients. Obviously a bus pass is not much use when one can't get out of the house in the first place and family and friends have disappeared.

Invest in ME Newsletter for March 2011

Patients are left to live in Dickensian poverty as problems obtaining benefits lead to lack of everything from food to heating to broken cookers, washing machines, boilers, windows etc.

These severely ill patients living alone are incredibly vulnerable and in need of serious practical and medical help. The help they deserve and should be entitled to can only be achieved by changing the official attitude toward ME patients at all levels.

It is all very well talking about mind and body at an academic level but in real life if the body is not being fed and taken care of then there surely can't be any progress in one's health, mental or physical.

IIME is run by volunteers with no funding for help lines, phone bills or charity premises yet we receive a lot of calls for help from patients who have been let down by every agency whose job it is to do this kind of work. Once the patient's medical record states that a person has ME it seems the societal infrastructure established to support sick people in need either freezes and gets modified as ME is not seen as a 'real' illness - a legacy of the failed MRC policies and the abdication of responsibility by government, CMO and health departments.

This is why one cannot compromise.

Dr Harvey Alter's Closing Remarks at the Blood Products Advisory Committee Meeting -December 2010

"I'm absolutely convinced that when you define this disease by proper criteria, this is a very serious and significant medical disease, and not a psychological disease. It has the characteristics of a viral disease. It usually starts with a viral-like illness. If XMRV is not the causative agent -- and it may well not be -- there is still need by other groups to look for the next agent which may be the case."

<http://www.investinme.org/InfoCentre%20Topics%20Dr%20Harvey%20Alter%20OBPACM.htm>

NICE Response

NICE have rejected the called-for review of their guidelines for ME.

This is now postponed until 2013.

IIME submitted a response to NICE detailing our opinion as to why the existing guidelines needed to be reviewed - [click here](#)

Invest in ME Newsletter for March 2011

NIH Knowledge Committee Workshop

In Bethesda, USA, in April the NIH Satet of the Art Workshop on ME/CFS will bring together subject experts who will discuss multiple aspects of ME/CFS, including epidemiology, etiology, pathophysiology, diagnosis and treatment.

The workshop panelists will identify gaps in knowledge and opportunities for new biomedical research.

This event consists of presentations on the biomedical basis of ME only.

Topics included are infectious diseases, systems biology, immunology, neurology, excercise physiology and energy metabolism, diagnosis and biomarkers and treatment.

Patient representatives in the organising committee are Mary Schweitzer and Pat Fero who both have extensive experience of everything to do with the illness.

<https://www.infinityconferences.com/InfiniBase/Templates/157557/Index.htm>.

The event is able to be seen via webcast

We are hopeful that something positive will come out of this meeting.

With a disease lacking a diagnostic test everyone's an expert...everybody knows someone's niece or cousin twice removed who went to see Dr So-and-so and now she's climbing mountains. Each new regime might be 'the One' to set things moving in the right direction. They stretch from the sublime to the ridiculous but you must try them all lest "don't you ever want to recover?" These treatments aren't always benign, leaving you worse off than when you started, not to mention emotionally and financially. - *Alison Hunter 1993*

ME Awareness Month

For IiME May has always been [ME Awareness Month](#) - a month of possibilities to raise awareness about ME. We're happy to join with the WPI ([click here](#)) and also promote May as the month to raise awareness of neuroimmune diseases. Apart from the IiME international conference on 20th May we have also been 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 publication reaches 18,000 decision-makers in London and we hope we can gather support for future research.

Invest in ME Newsletter for March 2011

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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Invest in ME Newsletter for March 2011

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