

Welcome to the Invest in ME Newsletter for March/April 2010

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Invest in ME Funds UK Biomedical Research Study by WPI

After Dr Jonathan Kerr announced that the planned research proposals for which IiME were attempting to raise funds (the role of XMRV in modulation of NK cell cytotoxicity and NK cell gene abnormalities in ME/CFS patients and normal blood donors) was being withdrawn due to no CFS patients being found to have XMRV Invest in ME had to decide where our Biomedical Research Fund could be used.

We wrote to the WPI's research director, Dr Judy Mikovits, and asked how we could help counter the negative comments about recent WPI biomedical research being made by establishment organisations and even by some individuals who are known to ME patients.

Dr Mikovits replied to us that we needed to look at UK patients. So we then decided this was the best way forward and that we would attempt to fund WPI research on UK patients. Those IiME supporters who had contributed to the Kerr study were contacted with an offer to refund their contributions or use them for other biomedical research. It is a testament to the patients, carers and families who support IiME that all of them decided that IiME could use these funds for biomedical research.

In discussions with Dr Mikovits we then decided to fund the studies suggested by her - especially as this finally provided an opportunity for those who are severely affected and/or who are house- or bedbound to participate in biomedical research. And so the WPI UK studies were started.

Our statement was issued at the beginning of March - [click here](#). Due to these plans becoming public knowledge other patients applied to be included.

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To the great credit of the WPI they then extended the numbers allowed into the studies of UK patients at their own cost and it now consists of over two hundred.

It is ironic to think that UK patients have to go to an institute in USA (described by the Guardian newspaper as "a small private pathology laboratory in Reno, Nevada" - but described by IiME in 2007 as "this exciting development") to have these tests performed.

Ironic that whilst the MRC take two years to form yet another expert panel to discuss future research into ME and yet achieve nothing but a few meetings, that the PACE trials will soon be published to show that CBT and GET as the most effective treatments for ME, despite being comprehensively destroyed by Margaret Williams and Professor Malcolm Hooper in Magical Medicine.

Ironic that whilst the MRC panel hold meetings which still have no published minutes and produce no tangible benefit or any apparent decisions on funding of biomedical research, an advisor to a children's charity can be awarded £160,000 to study a hyped-up psychotherapy/training programme which has become a lucrative business for some and which anyone can practise with relatively little experience and no requirements for a medical qualification.

Ironic that establishment organisations and some spokespersons seek to downplay or negate any new biomedical research into ME yet refuse to take responsibility or make themselves accountable to patients (witness the correspondence between Professor Malcolm Hooper and NICE and the MRC and Invest in ME's letter to the Secretary of State and the Prime Minister later in the newsletter).

A situation is left to fester for a generation where the UK government refuses to act, the UK Chief Medical Officer refuses to lead, the UK Medical Research Council refuses to fund, where the UK National Institute of Clinical Excellence refuses to treat seriously and where some UK ME charities build themselves into powerful organisations and fail to represent the patients who fund them.

Yet a reverse irony of sorts is now becoming apparent - one turned back on those who fund and support the non-science behind the psychosocial approach to ME.

An irony where the demand from UK patients to participate in these new WPI UK studies, or in Dr Chia's enteroviral testing - and Dr Lerner's, Dr Peterson's or Professor De Meirleir's testing and treatment regimes - all demonstrate that decisions and responsibility for ME research and healthcare is no longer solely in the domain of these uncaring, unrepresentative and unelected officials but is taken back to the people.

A reverse irony where these same UK patients are themselves so desperate to get better that they grab on to the hope brought about by an institute in America (WPI) whose UK research is partly funded by one of the smallest, non-subscription based charities in the UK (Invest in ME).

The WPI may or may not prove causality or implication for the XMRV virus. But what they have done is to provide hope that biomedical research, proper science and dignity for patients

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- all key elements of a longer term strategy - will overcome the intransigence, apathy and deceit of those who have been instrumental in retaining a status quo of inactivity. And this is what makes the establishment organisations and individuals scared.

Research such as the WPI study in the UK, using IiME's comparatively meagre Biomedical Research Fund, is performing something which the establishment and those who are employed by the establishment to cast doubt, cannot contain.

It is giving patients hope and influence.

In our letter to the Prime Minister in July 2009 [[click here](#)] we reminded him of his words from the previous year whilst discussing the future National Health Service -

'It will not be the NHS of the passive patient - the NHS of the future will be one of patient power, patients engaged and taking greater control over their own health and their healthcare too.'

In a remarkable twist certainly not envisaged in the spin of Gordon Brown's original policy statement, patients are being engaged and taking greater control over their own health. Yet it is not the NHS or the UK government who are shaping the future of healthcare for UK ME patients.

Instead it is a "small pathology lab" in Nevada.

IiME would agree for once with the Prime Minister - **Power to the Patients.**

Further reading on XMRV:

Invest in ME Funding of biomedical research - [click here](#)

Look to the end - [click here](#)

Dr. Mary Schweitzer comments on XMRV - **Letter from America - Just the Beginning** - [click here](#)

A recent Japanese study of XMRV - [click here](#)

To illustrate that the XMRV research is going to change things then a recent study is now holding out the hope that drugs used for HIV may hold promise for effective use in treating the XMRV virus and, by implication, also ME - [click here](#)

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



The interest in the 5th Invest in ME biomedical research conference is higher than ever this year and reflects the new optimism that myalgic encephalomyelitis is an area of research which is of more and more interest for microbiologists and healthcare providers. Our Conference News page carries updates with recent news.

Conference News

Annette Whittemore

We are pleased to announce that Mrs Annette Whittemore, Founder and President of the Whittemore-Peterson Institute for Neuro-Immune Diseases, will be attending. This will be Annette's third visit to the Invest in ME conference and we are indebted to her for the support given by the WPI.

Dr Ian Gibson

We are also pleased to announce that Dr Ian Gibson has accepted an IiME invitation to the conference. Dr Gibson opened the very first Invest in ME biomedical conference in 2006 and was responsible for the Gibson inquiry of the same year.

Conference Programme

We have finalised the programme for the conference - available here on the [conference web site](#).

Conference Sponsorship

IiME would like to say a big thank you to IMET who again will sponsor the expenses of a speaker for the conference this year. IMET are good friends of IiME and have given on many occasions to biomedical research into ME - the most recent being the research being performed by Professor Blomberg in Sweden. IMET are also a driving force in the European ME Alliance and were instrumental in the setting up of EMEA.



Conference Programme

Conference Flyer and Poster - [click here](#)

Conference Agenda - [click here](#)

Conference Registration - [click here](#)

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Invitation to BMJ Editor

Recently there have been several articles in the British Medical Journal regarding ME and much prominence has been given to comments about XMRV research. Invest in ME have mentioned before that the publicity being given to comments by individuals and to some research which seems to have been fast-tracked is out of proportion compared to the limited publicity given to the original WPI/National Cancer Institute/Cleveland Clinic study in Science magazine - at least in the UK.

The BMJ editor, Dr. Fiona Godlee, has commented recently -

[http://www.bmj.com/cgi/content/extract/340/mar04_1/c1266]

"The lively response to last month's editorial on chronic fatigue syndrome brings home the inadequacy of our current understanding of this condition, or group of conditions".

Invest in ME has written to Dr. Godlee and stated that it is not the inadequacy of our current understanding of this disease that needs to be brought home but rather the lack of correct education about ME and a lack of awareness of the advances in biomedical research into ME which are occurring. As the Invest in ME biomedical research conferences are meant to help correct this shortfall we therefore have invited the BMJ to this year's conference as our guest so that they may write an independent review of the research being presented. In this way we hope we can help the BMJ help doctors make better decisions.

Nowadays there is no excuse for ignorance when there is so much biomedical research available about ME and the BMJ has a duty to the public to present correct information rather than establishment bias based on opinions.



Fundraising for Invest in ME

We would like to mention the Students' Council of Malvern College, in Worcestershire, who have again raised money for Invest in ME. We have images, along with other recent events, on our fund-raising page - [click here](#).

Malvern College have been good friends of Invest in ME and it is to the credit of the young people at the college that they have taken on this role and contributed to our work. Whether it is the funding of WPI research, the organising and hosting of the international conference, producing educational material on ME, or simply allowing us to post copies of Lost Voices to those who may benefit from reading about severe ME - the contribution by Malvern (and our other supporters) means we can do such things.

Thank you to all our supporters for helping us.

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CFS RF Grant Applications

We are happy to agree to include a request from CFS Research Foundation to publicise their grant application from the Lancet of 23rd January 2010

CFS (Chronic Fatigue Syndrome) Research Foundation

Recent research funded by the Foundation has shown that multiple genes are either over or under expressed in the blood lymphocytes of CFS/ME patients when compared to those in normal controls. Because of the interest this has generated in relation to uncovering novel mechanisms, the Trustees now wish to extend into further genetic, immunological, physiological and other relevant scientific fields to pursue the cause(s) of this complex disorder(s).

The Foundation seeks project applications for grants of 1-3 year duration.

Applications will be subject to peer review by external referees and members of the Foundation's Research Committee.

Applicants should contact the Hon Director, CFS Research Foundation, 2 The Briars, Sarratt, Herts WD3 6AU or by email to cfsresearch@btconnect.com

Magical Medicine

Professor Stephen Holgate is on the research committee of CFS RF. He also heads the Medical Research Council panel involved in determining future research into ME mentioned in our last newsletter.

Although our funding of biomedical research has switched from Dr Kerr to WPI we nevertheless expected a response from Professor Stephen Holgate when we wrote to him ([see February newsletter](#)) inviting him to consider our funding request and to standardise on usage of the Canadian Consensus criteria for selecting patients for all future research into ME. Yet again we have not received an acknowledgement let alone a reply from Professor Holgate. Such is the lack of accountability of the MRC - let alone common courtesy.

IiME recently also wrote to the Secretary of State for Health Mr Andy Burnham ([click here](#)) following comments made by the minister responsible for long-term health conditions Mrs Ann Keen.

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We are still awaiting a response

As the run-up to the election takes place our ME and My MP Election pages are supplemented by responses from two Conservative MPs. We sent a copy of our letter to the secretary of state for health to Mr David Cameron - Conservative party leader.

One Norfolk constituent also sent a copy of the letter to their local MP - Mr. Keith Simpson (Conservative MP for mid Norfolk). Keith Simpson did not appear to bother to read the letter thoroughly, returned a template letter that would have done justice to the Department of Health and even confused the constituent with having ME when it had been made clear that the constituent's children were affected. It is clear that the Conservative representative for mid-Norfolk has no intention of treating ME seriously.

Mr. Cameron's office passed our letter to Mrs Ann Milton, Shadow Minister for Health.

The responses from the Conservative party can be found - [click here](#).

The template approach to handling our questions reminds one of how similar the two main parties are in their treatment of ME.

The chairman of NICE, Sir Michael Rawlins, is another who seems not to feel the need to take accountability for the status of healthcare provision of ME in the UK. He declined to respond to a request from Professor Malcolm Hooper to read the Magical medicine document - stating that he is not prepared to enter into correspondence on this matter ([click here](#)).

Professor Hooper's response [is here](#).

Professor Hooper has recently written to the MRC also - [click here](#).

The full list of Magical Medicine links are available - [click here](#).

Magical Medicine – PACE Trial Costs

The cost of the PACE Trials seems now to be nearer to £5 million with an extra £700,000 being granted in the last two years.

The involvement of the Department of Work and Pensions, in addition to the involvement of known proponents of the psychosocial view of ME, should clearly set alarm bells ringing for the media in this country.

The PACE trials clearly demonstrate the hypocrisy of the Medical Research Council's public statement -

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"All proposals for MRC grant funding are assessed through a two-stage process involving independent expert reviewers and the MRC research boards/panels. The core assessment criteria are the importance of the scientific questions being asked, the research programme's potential for advancing biomedical science, and the justification for the resources requested.

Ideally every research proposal we receive is reviewed by at least three independent scientific experts before the MRC decides whether or not to fund it.

These independent reviewers judge the quality of the proposed science, whether it addresses an important health question, and whether the study is appropriately designed to meet its aims. Known as peer review, this process is the internationally recognised method for ensuring quality control in science."

The MRC peer-review process, certainly regarding ME, is much like the rest of the MRC's workings regarding ME - negligent, clearly in need of an overhaul and needing to be made accountable.

Lightning Process - The Falsehood of Magical Medicine

When ME biomedical research and researchers have been starved of funding by the UK Medical Research Council it is particularly galling to hear that the charity AYME's medical advisor, Esther Crawley, is to receive £160,000 from the Linbury Trust and the Ashden Trust to look at the psycho-therapy which is the Lightning process [<http://www.bristol.ac.uk/ccah/news/2010/22.html#dresthercrawley>].

Not only is this a waste of scarce resources but children aged 8-18 are to be used to perform this study. There are many stories of the damage this series of courses can do to patients - a business enterprise which is unregulated, has no valid research into the "theory" behind it which really warrants funding of it (certainly not in preference to the funding of biomedical research into ME) and for which anyone can seemingly attend a few courses and set up a business, with no medical training.

This reminds us of a similar psychological approach to ME which that same charity discussed in a conference in 2005 - Reverse Therapy (RT) - with their then medical advisor, child psychiatrist Dr Derek Proudlove, who reported on his successful pilot study on RT. Five years on and children with ME are still ill but now we have another expensive training programme attracting the attention of another medical advisor.

We thought to check the definition of a pyramid business -

"A successful pyramid scheme combines a fake yet seemingly credible business with a simple-to-understand yet sophisticated-sounding money-making formula which is used for profit".

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Those who subscribe to organisations who market, advocate or advertise businesses under the guise of treatments for vulnerable and chronically ill people might reflect on the policy of the charity they are supporting.

If this training programme really needs research then why not start with adults who can give informed consent - and why not test it on a well known patient group with clear biomarkers such as diabetics or MS patients to see if these patients stop "doing" diabetes or MS after three days of training. Why are ME patients always the target for therapy businesses? If there is funding available for research into ME then why not direct it to biomedical research?

Farewell to the CMO

We have discussed the attitude and performance of the UK Chief Medical Officer before. Sir Liam Donaldson, having again declined to attend the Invest in ME conference and declined to meet with European ME Alliance in London, is content to leave office with the landscape of ME suffering looking like a train crash - with no policy to address the continued suffering of seriously ill patients, no regard for promising treatments for ME, no comment on the need for biomedical research into ME and no idea how to deal with any potential implication for the UK blood supply from the recent XMRV research.

For Sir Liam failure is an option - a status which obliterates all of the fine words which fill his web site at the Department of Health.

Lack of any urgency of the need for action and leadership by the CMO was always apparent.

Read this story of a seriously ill patient pleading for action from the most senior medical authority in the country -

"However, if every health professional you subsequently meet - be that for acute care in an A & E unit or resources from a wheelchair assessment advisor - if every health professional you meet then doesn't believe in M.E. it's of very little practical value when you seek services. Worse than that, it can actually be **detrimental to the service user-service provider relationship to mention that you have this condition.**

Once the M.E. diagnosis comes up, all the negative responses ensue."

"After 3-4 weeks the doctors said that there was nothing they could do to help me and they "were not interested in the aetiology of this illness". I was told that I should return home as they didn't know what to do with me and my health was probably being worsened by the conditions on a general ward"

Please read this story in full. It is a story describing much of the desperate situation facing people with ME and their families in the UK today. Yet this was written to the CMO ten years ago! The full story is available - [click here](#).

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Media News

A fascinating 1996 feature from the USA's "Prime Time Live" about ME, which coincided with the debut of Hillary Johnson's book, *Osler's Web*. The video - at <http://www.rescindinc.org/primetime1996.wmv> - brings the history of many of the USA's main players together. If one never understood the full USA ME story then this video may make sense of it all.

Director Pål Winsents from Norway has completed a film focusing on the experiences of writer Anette Gilje, who was diagnosed with ME in 2000, following a virus infection which started in 1995. With the diagnosis she has come to terms with her situation, and managed to write three books despite her illness. The film follows Anette on a journey to explore all the available treatment on the market in an endless effort to get well whilst hae="Verdana">The film mentioned in our October newsletter has come a step closer and a new web site has been created - <http://www.whataboutme.biz/>



News from the European ME Alliance

The European ME Alliance contacted health ministers and Chief Medical officers of nine European countries. More details are here - [click here](#). So far the UK, Norwegian, Italian, Spanish and French health ministers/CMOs have declined.

ME Awareness March for ME

Ali Head is organising a March for ME on 12th May in Westminster, London. If you wish to participate or help with the event then contact Ali via the facebook site set up for the event -

<http://www.facebook.com/event.php?eid=188885688692&ref=ts>

Easy Fundraising for iME

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.



NEWSLETTER

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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.



Contacts:

All inquiries to Invest in ME - info@investinme.org

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Lost Voices

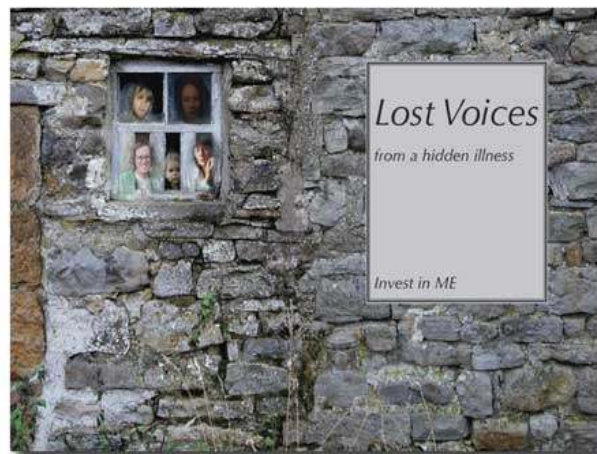
Providing a voice for those severely affected with myalgic encephalomyelitis

Invest in ME are offering a second edition of this book which will help healthcare professionals, media, ME Support groups and people with ME in their quest to improve education regarding Myalgic Encephalomyelitis (ME).

The name 'Lost Voices' refers both to the fact that people who are severely ill with ME are generally not in a position to make themselves heard, and also to the way that the prejudiced denial of ME - as an 'aberrant belief' rather than a devastating physical illness - has meant that often others are incapable of actually hearing and seeing what is being said and shown. 'Lost Voices' is primarily written by people affected by severe ME- whether as sufferers, carers or families. The book provides the following -

- It provides an opportunity for people who are usually invisible and unheard to speak for themselves, so that their situation can be seen and understood more clearly
- It clearly and movingly shows the evidence of the devastating impact this physical disease has on individuals and their carers and families
- It will bring to more public notice the plight of ME sufferers
- It will help change a widespread lack of comprehension based on general misinformation, vague definitions and manufactured statistics, to the development of empathy and concern for those who are so ill
- It can educate the medical profession, the public and others such as wider family
- It encourages a sense of community among ME sufferers and those supporting them

The book is an A4 landscape size with a laminated card cover. The stories and photographs are provided by carers, families and, as far as possible, people with ME themselves. 'Lost Voices' represents different families, showing the impact of the illness on all family members and sufferers and carers.



For other educational material, including our **International ME/CFS conference DVDs** go to <http://www.investinme.org/InfoCentre%20Education%20Homepage.htm>