



NEWSLETTER

Welcome to the Invest in ME Newsletter for October 2009

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THE PROOF IS OUT THERE - PART III

The news we had been awaiting since May was finally announced. The research on a novel virus to which Dr. Judy Mikovits alluded at 4th Invest in ME International ME/CFS Conference in May, in answer to a question from Hillary Johnson, has been published by [Science magazine](#). The researchers at the Whittemore-Peterson Institute (WPI), together with the Cleveland Clinic and the National Cancer Institute have reported that 67% of 101 ME patients tested positive for infection with xenobiotic murine retrovirus (XMRV), a gammaretrovirus associated with a subset of prostate cancer. Only 3.7% of 218 healthy subjects tested were positive for the virus.

People with CFS are 54 times more likely to be infected with XMRV than your average person on the street - [<http://en.wikipedia.org/wiki/Xmrv>]

The implications here that ME is indeed an infectious illness could be far reaching.



Yet the US Centres for Disease Control (CDC) knew of the possible retrovirus link back in 1991 when Elaine De Freitas presented research on this. The CDC failed to act - much as the UK MRC have failed to act in all the years despite the scandal of suffering being caused to tens of thousands of severely ill people.

Predictably some of those who continue to portray the illness as a somatoform condition have immediately tried to diminish the research - an obvious sign that those vested interests which have dominated research funding from the MRC for so long are worried that their cash cow is about to be culled by good science.

More details - [click here](#).

Statement by Invest in ME on the WPI research - [click here](#).

Read Hillary Johnson's view of this news - [click here](#).



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WPI COLLABORATION

It was good to learn at the IiME conference in London that the WPI's Dr Mikovits and Dr Jonathan Kerr were working together and had been awarded a \$1.6 million grant by the National Institute of Allergy And Infectious Diseases. This grant spans 5 years and will provide critical support for the ongoing research into the causes and diagnosis of neuro-immune diseases.

It is immensely encouraging to know that one of our key requirements, namely international collaboration on biomedical research into ME, is thriving - more reason to direct fundraising to such programmes as those of the WPI and Dr Kerr. IiME's Biomedical Research Fund is aimed at assisting in this area also.

How ironic that the UK's leading ME researcher should have to find funding from the USA when the UK's supposedly independent MRC has so consistently failed to provide anything.

CANADIAN GUIDELINES

Invest in ME are UK distributors of the Canadian Guidelines Consensus document. We provide these booklets to organisations and individuals in the UK and to other charities and organisations such as the Grace Charity, Brame, MEA and Forget-ME-Nots. We have also supplied them to other countries in Europe - Ireland, Sweden, Germany and Belgium.

IiME provide these on a not-for-profit basis - 80p per copy plus postage and packaging. To order the Guidelines [contact IiME](#).

MARTIN LERNER - ENERGY INDEX POINT SCORE

Dr Martin Lerner is now treating a number of UK patients on antiviral medicines - apparently supported by their medical insurance.

Dr Lerner's Energy Index Point Score (EIPS TM) is now a fully registered U.S. trademark. It is freely useable and may be referred to as "Reg. US Pat. Off." or "Reg. U.S. Pat and Tm Off."

[See the EIPS here.](#)

RESPONSE FROM CMO

As we reported in our September newsletter Invest in ME have written again to the CMO regarding H1N1 influenza virus and the development of a vaccine. The reply mixes ME and chronic fatigue. It didn't answer our questions on the differences between the information on the CMO and the DoH web pages.

The CMO has replied - [see here](#).



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PROJECTS

We mentioned in our September Newsletter Supplement that we were involved in some new projects.

International ME/CFS Conference 2010

Our fifth Invest in ME International ME/CFS Conference is scheduled for central London in May 2010. We hope to bring more details shortly.

Two other projects concern films relating to ME.

Film on ME

One of these films is a feature-length documentary about ME and the struggle to get the illness recognised by the medical profession. This film is aimed at showing the way ME has been treated, both in the UK and abroad.

For this the film producers would like to find people with ME who would be willing to be interviewed with a view to being included in this documentary.

Although all stories are welcome of special interest would be those who contracted the illness in the 1980s, those who have been misdiagnosed or were treated with CBT and/or GET and got worse because of it.

The film makers are especially looking for intriguing and interesting stories that convey the devastation of ME or where promising careers have been affected by this illness.

We are hoping to receive stories not just from the UK but from Europe also and we hope the contacts within our European ME Alliance (www.europeanmealliance.org) may help us.

All details received will be treated confidentially and only passed to the film researchers, who will then be in contact with those who have offered their participation.

Invest in ME will acknowledge all receipt of stories from those contacting us.

If you are interested in contributing please contact us at -

Invest in ME
PO Box 561
Eastleigh SO50 0GQ
Hampshire

or email us [here at IiME](#). Include Name, Email address (if applicable), Postal Address and Contact telephone Number (if possible). Also required are Year contracted ME, Year ME diagnosed, who and how diagnosed and any further information about your story (initially a maximum of about 300 words) - perhaps detailing your life/career before becoming ill and how the illness has affected your life.



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Invest in ME will pass this information to the film producers having made them aware that this information is not to be shared with any other person or organization without your permission.

Lost Voices

As mentioned last month we are nearing the end of our current batch of Lost Voices, having distributed the book to seventeen countries. Thanks to donations made by supporters Lost Voices now appears in medical and public libraries – the latest being West Middlesex University Hospital NHS Trust.

Invest in ME have self funded the cost and distribution of nearly 250 copies of Lost Voices to politicians, journalists, television and radio presenters, doctors, ME advocates, healthcare staff and to others whom we thought would help raise awareness of ME or be instrumental in changing perception regarding ME - the latest being a copy to be sent to the Director of Secondary Care, DHSSPS in Ireland.

Lost Voices has been included in study material for courses on 'The Chronic Illness Experience' at De Paul University, Chicago, USA, an important centre involved in ME/CFS research where Invest in ME have offered to supply the book for free for future courses. Via one of our great supporters in the USA a copy of Lost Voices has even found its way to the White House. Sadly we also sent a copy to the Prime Minister's wife but received neither acknowledgement of receipt nor any indication that the book had been read.

Lost Voices has met with widespread appreciation from patients, carers, family, friends, doctors, consultants, researchers and MPs concerned about the plight of sufferers. There is clearly a need for such a book, so Invest in ME are looking for help with funds to order a second batch of Lost Voices. We intend to distribute the book as far and as wide as our resources allow and we have grant applications in to try to help in this endeavour. If we are unsuccessful in these grant applications then IiME's trustees themselves will attempt to fund directly another batch of the books.

In the meantime an update on the book project is a development - into a film -

'Lost Voices and the Emperor's new robes... but what has happened to his clothes?'

Lost Voices briefly touched on the differing views of ME ranging from those underpinned by decades of biomedical research to those derived from outdated assumptions and supported by research based on an unrepresentative and heterogeneous patient base. The film "Lost Voices and the Emperor's new robes... but what has happened to his clothes?" will continue to explore these powerful and neglected issues.

This is not a film about living with ME, but reveals how support for psychiatric and psychosocial perspectives and the spread of misinformation have severely affected and even destroyed the lives of many people with a severe neuroimmune disease.

'Lost voices and the Emperor's new robes... but what has happened to his clothes?'

is the working title and is being made by the same team who undertook the original book project - an ME patient's family with a mix of relevant skills and committed personal involvement. The first stages of filming are already underway with contributions from doctors,



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consultants, researchers, sufferers and their families. Subsequent stages will develop this into a well-informed, evocative and powerful film where some of the contributors to 'Lost Voices' will be included, as well as some very welcome new participants. Invest in ME will bring more news on this project as it develops. The Lost Voices will continue to be heard.

Petition Against the CFS Empiric Criteria

There is still time for all ME patients, groups and carers to sign the petition against the CFS empiric criteria (Reeves, 2005). This is the definition which the Centres for Diseases Control in USA have suggested be used. The definition is rightly criticised by the ME community as a mockery of correct science.

Anyone having listened to Hillary Johnson's presentation in London in May on the Influence of the CDC on ME Around the World would be left in no doubt as to the total bias, ineptitude and flagrant corruption in the CDC with regard to the treatment of ME.

A meeting of the CFS Advisory Committee at the end of October is planned. The CDC will be announcing their 5-year plan and the dangers of leaving in place this sub-standard, unscientific and flawed definition in place will lead to further problems for people with ME and their families in the years ahead.

Invest in ME have rightly criticised the biased approach of the UK Medical Research Council in their treatment of ME. The CDC need to be fought in much the same way as their approach to ME has so much in common with the MRC approach. In fact it has been stated that Dr. Bill Reeves (head of the CFS programme at the CDC) is in close contact with at least one of the psychiatrists who form the part of the MRC's panel supposedly looking at future research into ME!

Defining ME patients by using a large heterogeneous group of with non-representative symptoms is the falsehood allowed to be perpetrated by the MRC when wasting millions of pounds on flawed research.

The [link to the petition is here](#).

The petition is open to all people - even those outside USA.

Christmas 2009

Invest in ME don't do Christmas cards. But we do still have some copies of Lost Voices left from the batch which we originally commissioned and these would make ideal Christmas presents.

Lost Voices is ideal for anyone needing to know the reality of ME and yet also to show the commitment of carers, the optimism and tenacity of patients who fight on in despite the appalling situations they are left in by the health services. Lost Voices is about hope and resilience.



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The IiME conference DVDs also could make useful presents. Every IiME conference DVD contains the conference lectures which are easily navigated via a menu option. They can be used by healthcare staff to claim their necessary Continuous Professional Development (CPD) points.

If you are thinking of what to give at Christmas then please help Invest in ME and consider Lost Voices or the DVDs.

[Lost Voices - Order here](#)

[Conference DVDs - Order here](#)

Best wishes to all

Invest in ME

Support Invest in ME - support biomedical research

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:

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

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