



# NEWSLETTER

## Welcome to the Invest in ME Newsletter for November 2009

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<b>IN THIS ISSUE</b>
<b>Our Supporters</b>
<b>5<sup>th</sup> IiME International ME Conference</b>
<b>ME As NOTIFIABLE ILLNESS - Letter to UK CMO</b>
<b>XMRV Research - A Landmark for ME</b>
<b>And the Parallel Worlds</b>
<b>CFSAC Meeting in Washington</b>
<b>ME Story</b>
<b>CBT and GET</b>
<b>Dr Martin Lerner Statement</b>
<b>Films on ME</b>
<b>ME &amp; My MP</b>

### For Our Supporters

We would like to send a message to all those who have helped us recently and in the past. We are grateful for the help and advice provided by both patients and healthcare professionals when trying to help those who have contacted us in serious situations. We also would like to thank those who have made, or continue to make donations to Invest in ME. The support we receive, from all parts of the UK, and even from other countries, makes it worthwhile continuing. There are many names there for us to thank - we hope you realise how much we appreciate your support. Thank you.

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

The Invest in ME 2010 biomedical research conference is set for 24th May 2010 in Westminster, London. This will be our fifth international biomedical research conference and it could not come at a better time for people with ME and their families.

The outstanding XMRV research from the Whittemore-Peterson Institute and their colleagues from the National Cancer Institute and the Cleveland Clinic mean that ME is now centre stage and it is an opportune time to get healthcare staff to come to the conference and listen to the latest research and news. With more researchers now prepared to enter this field we feel this could be the most useful conference yet.

In order to convey that significance we have invited Sir Liam Donaldson, the Chief Medical Officer of the UK, to open the conference. This will be the fifth time we have invited the CMO and the third time he has been invited to open our conference. As with many other areas the



# NEWSLETTER

November 2009

XMRV research has opened up this possibility for increasing the awareness of the severity of this illness. Look out for more news of the conference as we build up the conference web site - [see <http://tinyurl.com/ykdoqkc>].

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## ME AS NOTIFIABLE ILLNESS - LETTER TO THE UK CMO

We have set up a new page containing a few of our letters to the CMO [see - <http://tinyurl.com/yz4qvzz>].

Our latest letter asks the CMO to consider making ME a notifiable illness, not just at schools as we have requested before, but for the entire general population. We do this not to gather statistics but because the recent XMRV research has possibly serious implications for the public as an infectious disease and as a health risk.

Our letter, sent on 26th October, has suggested that the XMRV research now means that the general population needs to be protected against the consequences of this virus and the CMO must now make ME his personal responsibility.

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## XMRV RESEARCH - A LANDMARK FOR ME

Some years ago those suffering from diabetes and Multiple Sclerosis (MS) were denigrated and trivialised by the same type of establishment corruption which has been directed toward ME sufferers. Both diabetes and MS were illnesses which were regarded as psychiatric until insulin and MRI were discovered. The ability of an MRI scan to show the pathology of MS destroyed the psychiatrists who wished to portray that illness as "women's hysteria".

The discovery by the Whittemore-Peterson, the National Cancer Institute and the Cleveland Clinic researchers of xenotropic murine leukemia virus-related virus (XMRV) in ME patients may well be the equivalent defining moment for ME.

As our letter to the CMO in 2006 [<http://tinyurl.com/yzn3j4g>] stated - "although there is much to learn about the details of these illnesses our present understanding and treatments have emerged from careful research studies that have exposed the inadequacies of the psychiatric models".

The WPI has tested more samples since submitting the first paper and our **European ME Alliance** [<http://www.euro-me.org>] colleagues report of the interest around Europe in studying this. One Swedish clinical virologist has described this research as important as the discovery of HIV and already there are plans for studying this in Swedish ME patients.

The news of the XMRV research is really encouraging in bringing ME into the main stream media coverage and getting new researchers interested in the field, and wanting to reproduce the results. This is exactly what ME needs - to be perceived and treated as a mainstream organic illness needing funding to provide correct treatments.



# NEWSLETTER

**November 2009**

Although the discovery is quite serious, as it is a retrovirus and therefore has its own consequences, we feel it is better in the long term for patients to know what is wrong with them rather than continually being left in limbo due to ignorance and outdated information.

Researchers will now have to study the XMRV virus, how it behaves etc. and it is necessary for governments and healthcare organisations to treat ME with the urgency it requires. We now have another biomarker which, of course, needs to be verified by other researchers first before we can be absolutely certain of its importance. There are bound to be people in support groups who have different reasons for their illness and we need biomarkers to make sure a diagnosis given is a correct one.

The WPI website states:

"We have detected the retroviral infection XMRV is greater than 95% of the more than 200 ME/CFS, Fibromyalgia, Atypical MS patients tested. The current working hypothesis is that XMRV infection of B, T, NK and other cells of the innate immune response causes the chronic inflammation and immune deficiency resulting in an inability to mount an effective immune response to opportunistic infections."

Interestingly, in a discussion after this year's IiME Pre-Conference Dinner presentation by Hillary Johnson, Professor Harald Nyland mentioned how some diseases need two viruses for a disease to develop. He also mentioned Burkitt's lymphoma as an example where the presence of two viruses, EBV and malaria is needed.

The elapsed time taken by Science magazine in publishing the research findings may be seen as proof of the excellence of the work being performed by the team of researchers at the WPI, the NCI and the Cleveland Clinic.

There have been comments about Lombardi et al. not giving demographic details of the patients and controls used in the recently published XMRV study. Scientific journals have all their own rules governing the format in which they want research articles written. This XMRV study has been written according to the rules given by the Science magazine and all other interested researchers can request more detailed information on methodology etc. if they wish.

For Science to publish an article on ME is a landmark itself and has a huge positive effect on all biomedical ME research. Having the National Cancer Institute and the Cleveland Clinic working with the WPI and publishing these results, in a journal of the calibre of Science, is as good as it gets. This work should open up more funding opportunities for other existing biomedical ME researchers.

If the WPI and subsequent research does not conclusively prove that XMRV is the cause of ME it will at least have interested more researchers to participate in biomedical research in this area. And will have broken the mould.

We should all take this opportunity to make a real push for funding for more biomedical studies based on homogenous well defined patient groups. IiME will continue to campaign for biomedical research, and apply for grants for biomedical research, in the sure knowledge that good science eventually will win through.



# NEWSLETTER

November 2009

Our view on the XMRV research is echoed by the words of Professor Martin Pall, a speaker at our 2007 conference -

"There have been comments in the media to the effect that this finally shows that CFS/ME is physiological, not psychological. This is true, but this should have been obviously true anyway, at least six or seven years ago. Nevertheless the media coverage of CFS/ME obtained by Mikovits and her colleagues must be viewed as a true gift to those interested in extending public knowledge of this disease."

**The discovery of XMRV in ME patients has changed the ME/CFS landscape for good.**

We have more detail on the XMRV research – [see <http://tinyurl.com/ykxx9jn>].

Our statement on the research was published here [<http://tinyurl.com/yhxbxtm>].

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## And The PARALLEL WORLDS...

We disagree with those who seem to wish to downplay the WPI research on XMRV.

The status quo regarding ME is unacceptable. It benefits only those who make a living out of inactivity or only slow progress. It benefits those who wish to maintain the myth of ME being poorly understood.

In order to illustrate why we need to alter direction from the past and discard those who will not change, we only have to revisit the UK Medical Research Council policy on ME - with yet another reincarnation of an ME expert panel due to convene in a workshop to discuss research requirements in November, after a two year gestation period (ironically, the same amount of time that it has taken the WPI to achieve this breakthrough).

In our previous newsletters [<http://tinyurl.com/ydov9oe>] we have criticised the MRC policies toward ME over the last decade and lambasted their lack of significant progress since discussing the set up of the latest panel of "experts" to look at research strategies for ME. We mentioned that the guidelines to define ME for this panel were not specified and that this would have a dramatic effect on any research chosen to be funded. We also questioned the peer reviewing system which would endorse research proposals - a major failing of the MRC policy on ME in the past.

Now there are rumours that those who see ME as a somatoform condition and who sit on the MRC panel may be considering performing research on XMRV, and in all likelihood will be using the flawed diagnostic criteria of the PACE trials to determine cohorts of patients which would include heterogeneous groups - an action which would totally skew results.

This, of course, has been the problem with MRC research over the last generation. The forces within the MRC panel who wish to treat ME as somatoform illness and eliminate ME from the WHO ICD-10 G93.3 category as a neurological illness, will not wish to change things.



# NEWSLETTER

**November 2009**

Invest in ME called on the MRC and the government to acknowledge the XMRV research and implement a strategy of funding for biomedical research (as most know we facilitated invitations to the MRC and the DoH and the CMO to visit the WPI at our 2008 iIME International conference in London - all declined or unanswered).

We would like the MRC to remove from the current panel those who have a track-record of researching ME as a somatoform illness, and re-establish it with those who are able and willing to perform biomedical research in the light of the news from the WPI.

The involvement of the ME community on the panel should similarly be changed to be more representative of those viewing ME as an organic illness. Certainly the workings of any future MRC initiatives with ME should be made totally transparent.

Close cooperation on future research should be performed with the WPI. Funding should be made available to establish a strategy of biomedical research into ME.

This is now a time for bold moves by the government, by the MRC and by the CMO.

There is no more need for a so called "balanced approach". An unequivocal change in emphasis must now be made by the MRC toward a policy of biomedical research. The MRC must be forced to change their policies and perform the role it publicises for itself with its four stated strategic aims -

- 1** Picking research that delivers: Setting research priorities which are most likely to deliver improved health outcomes.
- 2** Research to people: Bringing the benefits of excellent research to all sections of society.
- 3** Going global: Accelerating progress in international health research.
- 4** Supporting scientists: Sustaining a robust and flourishing environment for world-class medical research.

Let's hope that the new wave of interest in biomedical research which the WPI research has generated will be to the benefit of all genuine biomedical researchers carrying out valuable work in the field of ME.

We hope to increase our Biomedical Research Fund by stepping up our grant applications in an attempt to help organisations such as WPI and the European ME Alliance and others in UK and Europe who wish to perform serious biomedical research. The fund is described here [<http://tinyurl.com/ydh6whu>].

We will attempt to implement other projects relating to severe ME. We invite people to support us in these ventures.

The "Can Do" attitude shown by the WPI is the way forward.



# NEWSLETTER

November 2009

## CFS Advisory Committee Meeting Washington

The USA CFS Advisory Committee (CFSAC) -which provides advice and recommendations to the Secretary of Health and Human Services on issues related to ME/CFS, held a two day hearing in Washington on 29-30 October and much of it was related to the newly discovered human retrovirus XMRV. The proceedings can be viewed - ([here for Day 1](http://videocast.nih.gov/launch.asp?15408) - <http://videocast.nih.gov/launch.asp?15408>) and ([here for Day 2](http://videocast.nih.gov/launch.asp?15409) - <http://videocast.nih.gov/launch.asp?15409>).

Among those presenting were Dr Daniel Peterson and Mrs Annette Whittemore from the WPI. The Centres for Disease Control (CDC)'s research policy on ME/CFS was widely condemned and this, by default, also condemns the past UK Medical Research Council policies, as those influencing UK policy on ME have been working in close collaboration with the CDC.

With widespread concern about the XMRV retrovirus and the implications for the general population the CFSAC hearings in Washington produced the following statement from the Department of Health and Human Services (HHS) -

Xenotropic Murine LeukemiaVirus-Related Virus (XMRV)  
Blood Safety and Availability  
Office of Public Health and Science  
Department of Health and Human Services (HHS)

Jerry A. Holmberg, PhD, SBB  
October 30, 2009

The Office of Public Health and Science's Blood Safety and Availability is aware of the recent literature suggesting linkage of chronic fatigue syndrome to a possible contagious rodent retrovirus, XMRV. XMRV has also been associated with an aggressive form of prostate cancer. Antibodies against the virus have been detected in 3.7% of healthy controls in a study of a small number of individuals. Currently there is no commercially available test for infection with XMRV. While there is no known association of CFS or prostate cancer with history of transfusion, the finding that the virus is associated with white blood cells has led some to question whether XMRV could be transmitted by transfusion and might therefore pose a threat to the health of blood recipients and potentially also transplant recipients.

The HHS Blood Safety Committee works with all the PHS agencies (i.e., CDC, FDA, HRSA, and NIH) to ensure the safety and availability of blood products as well as transplantation safety. Under the leadership of that committee, steps are being taken to investigate the blood safety threat from XMRV and the potentially protective role of white cell removal, which is performed on approximately 70% of blood. An interagency Emerging Infectious Diseases working group that reports to the Blood Safety Committee is currently assessing the literature on XMRV, conducting meetings with experts on this retrovirus, and interacting with groups that could study the question of blood safety. A report is expected within several weeks. In particular, the National Heart Lung and Blood Institute Retrovirus Epidemiology Donor Study-II



# NEWSLETTER

November 2009

(REDS-II) investigators are aware of the report in Science and are assessing the prevalence of XMRV in blood donors to determine whether studies aimed at evaluating transfusion-transmission rate are warranted using NHLBI's repositories of donor and recipient blood samples.

HHS will remain vigilant in assessing the safety of the blood supply and developing interventions as appropriate.

The CFSAC hearings demonstrated the need for change in establishment organisations. As with the flawed MRC policies in the UK the USA also has its problems with the failings of the CDC clearly on show for all to see.

The prime responsibility for these failings was placed firmly at the door of the leader of CFS research at the CDC - Dr William Reeves. The underwhelming comments of Dr. Reeves after the WPI research was published (see New York Times - <http://tinyurl.com/yjmmk7p>) in which he stated that "My expectation is that we will not (confirm finding XMRV in ME patients)." show not only the contempt for people with ME that is well known in the UK but also the intransigence which has dominated CDC policies on ME for a generation.

The CDC policies toward ME are now long overdue for a change.

Dr. Reeves' tenure in charge of CDC policy on ME must surely now be quickly brought to a close.

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## ME Story - Misdiagnosis/Missed Diagnoses

Misdiagnosis and missed diagnoses are the end products of a system which has failed to tackle this illness.

This story from Christine Wrightson is testament to the failings of a generation of policy-based evidence making from the UK government and the MRC.

For the full story [see <http://www.investinme.org/mestory0041.htm>].

Christine has requested a Public Enquiry/Full Medical review into why hypopituitarism/secondary hypoadrenalism (pituitary disease) is not recognised and properly researched. She has sent her story to all MPs in order to make them aware of the dangers of misdiagnosis and also of the seriousness of this illness.

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## CBT and GET

With the flawed and wasteful PACE trials to be published next year we would like to publicise the paper by Frank Twisk and Dr Michael Maes who have written two excellent articles refuting the benefits of GBT and GET for ME patients.



# NEWSLETTER

November 2009

A review on Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) in Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS): CBT/GET is not only ineffective and not evidence-based but also potentially harmful for many patients with ME/CFS – [see <http://tinyurl.com/ygqqe6r>].

The Belgian government has evaluated the outcome of treating ME patients with CBT/GET and concluded that they yield no significant improvement for people with ME and cannot be considered to be curative therapies – see [<http://tinyurl.com/ya8brxr>].

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## MARTIN LERNER - CALL TO ACTION STATEMENT

Amongst all the XMRV news Dr Martin Lerner issued a press statement - a call to action for use of a common language in CFS evaluation and treatment.

We remind people with ME how Martin Lerner recommended in his 2008 Invest in ME Conference lecture how patients should not exercise until they have reached level 7 on this EIPS scale – [see <http://www.investinme.org/InfoCentre%20library.htm#EIPS>].

See the statement here [<http://tinyurl.com/yabb9oz>].

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## FILMS on ME

Just a reminder that the film project on ME (a feature-length documentary about ME and the struggle to get the illness recognised by the medical profession) still needs to hear of patients who would like to provide their stories.

If you are interested in contributing please see our October newsletter for details – [see <http://tinyurl.com/yahorkh>].



From our European ME Alliance colleagues in Spain we have news of another film about ME. The film is on tour right now in Spain and is filling auditoriums with 300 people at a time and provoking discussion.

The film, **Amapola y los aviones: Documental sobre el Síndrome de la Fatiga Crónica**, is from Dziga Productions, a small Spanish film production company. This Spanish-language documentary on the voices of people who live with ME includes two men and two women with ME, who speak from their hearts about their interrupted lives, of their past, their hopes, their losses, their anger and their illnesses.

For Alfonso, a former construction worker, every word he utters in the documentary, is an effort: "My two daughters don't understand why I am so sick. They want to know when I will get better. But if things don't change much, the day I got sick was the day I died".





# NEWSLETTER

**November 2009**

Two doctors specialising in ME also appear in this documentary, sharing their thoughts. Argentinean-Spanish Dr Pablo Arnold says that the ME patient is like a lighthouse, always there, silently putting in evidence all that is wrong with our society. "That is why everyone, administrations, doctors, everyone, tries to get the person with ME out of the way".

Dr Nancy Klimas, with the help of subtitles, shares some of her thoughts in this documentary: "Yes, people with this illness are suffering a lot. But this society does not pay attention to suffering".

Read more on the Spanish site at [www.amapolaylosaviones.com](http://www.amapolaylosaviones.com).

Also in Spain Eva Caballé, a woman living with MCS in Barcelona, Spain, has just published a book about her experience:

<http://www.thecanaryreport.org/2009/11/01/interview-with-eva-caballe/>

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## **ME and My MP**

We have written again to the main political parties to tease out their policies toward ME and we invite people to send in their replies from MPs to their questions.

We have written to the Secretary of State for Health requesting a meeting with him along with a representation from the ME community which Invest in ME will organise. Only a direct meeting with the health minister himself will suffice due to the urgency and significance of the XMRV research.

With the XMRV research news it is also important to gauge the intentions of the main political parties in the run up to the election.

We have asked the following questions of each party -

- In the light of the recent XMRV research findings will you support calls to ensure that the Department of Health allocates adequate, ring-fenced funding for dedicated biomedical research into ME which uses cohorts diagnosed according to the Canadian Consensus Document?
- Will you support calls to make ME a notifiable illness now that the recent XMRV research has indicated ME is an infectious disease?
- Will you support Invest in ME in its request to modify the training curriculum for all doctors and nurses to ensure that they have an adequate understanding of the physiology of ME, knowledge of the Canadian Guidelines for diagnosing ME and knowledge of the latest biomedical research into ME.
- Will you encourage GPs to specialise in ME and appraise themselves of the latest biomedical research and possible treatments available?



# NEWSLETTER

November 2009

- Will you support Invest in ME in its attempts to set up a national centre of excellence for ME which will perform translational research into ME as an organic illness and provide treatments for all ME patients from the severe to the mildly affected?
- Will you support Invest in ME in its attempts for ambulatory services to be made available for all severely affected people with ME which would allow visits by ME specialists to the homes of those who are unable to visit hospitals or GPs?
- Will you encourage the Department of Work and Pensions to adequately train their assessors in the physiology of ME as a chronic neurological illness and provide disability forms which have questions which truly reflect the nature of this illness?

The ME & My MP Election page is here [<http://tinyurl.com/yjowsgs>].

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**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.



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### **Contacts:**

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