

Welcome to the Invest in ME Newsletter for October 2010

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Welcome to Invest in ME's October 2010 newsletter.

Round-Up of Research

It has been a while since our last newsletter. So a quick round-up of some of the research news -

Online Version of Lo et al. Paper

On 25 August 2010 the prestigious American Journal PNAS published its online version of the long awaited research paper by Lo et al. entitled 'Detection of MLV-related virus gene sequences in blood of patients with chronic fatigue syndrome and healthy blood donors'

[[click here](#)].

"The findings support a prior study that identified a similar virus in many CFS sufferers. However, it also conflicts with the results of several other studies that failed to detect gene sequences from either virus in CFS patients, raising questions about the PCR methods employed." - [click here](#).

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International Workshop on XMRV

Researchers and clinicians came together for the first International Workshop on XMRV in Bethesda, USA on 7-8 September 2010. The workshop was sponsored by the NIH Abbot Laboratories. The director of NIH, Francis Collins, opened the conference which shows high level interest in this newly discovered gamma retrovirus.

The Question and Answer session is available to be viewed here [<http://videocast.nih.gov/summary.asp?live=9582>] and journalist Mindy Kitei who attended the workshop writes about it here <http://www.cfscentral.com/>. A summary by Hillary Johnson is available on www.oslersweb.com. Hillary has vast knowledge of past history of ME/CFS so her observations are invaluable.

Invest in ME and our European ME Alliance partners Spain (Liga SFC), Ireland (IMET), Sweden (RME) and Germany (Fatigatio e.V.) were either contributing or closely involved in some of the studies that were presented at this workshop. XMRV was found in UK and Spanish patients but not in the German or Swedish ME patients according to the studies presented at this workshop. Professor Jonas Blomberg's team in Sweden was however able to identify 3/5 positive samples sent to him by the WPI so it shows that his methods worked.

A study by Villinger et al. found chronic XMRV infection in tissues of macaque monkeys but not in blood.

The UK studies which IiME part-funded are being prepared for publication by the WPI.

Abstracts and presentations of the first International XMRV Workshop are available here [http://www.virology-education.com/index.cfm/t/Workshop_material/vid/1A5D65BD-FB8B-8AE1-5E10829372D080B4].

Note: A separate German study by Fischer et al found XMRV via nasal swabs in immunocompromised patients which suggests possible transmission through respiratory secretions is likely.

Professor Anthony Komaroff Webinar

On 16 of October 2010 CFIDS Association of America hosted a webinar by Professor Anthony Komaroff in which he summed up the CFS/ME research up to now very well.

The recording is available to view again here - <http://www.cfids.org/webinar/091610.wmv> and the slides can be seen here <http://www.cfids.org/webinar/slides-091610.pdf>. The presentation is well worth watching as it is very easy to understand.

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Study Finds Oxidative Stress/Increased White Blood Cell Apoptosis in Children with ME

While the NIH/FDA study received no media coverage in the UK a study by Kennedy at al. from the Dundee University, Scotland received ample amount of media interest [<http://www.bbc.co.uk/news/health-11209605>]. This study which was started in 2006 investigated biochemical and vascular aspects of paediatric ME. Increased oxidative stress and increased white blood cell apoptosis was found to be present in these children. These results reflect earlier studies done on adult ME patients and point to viral infection.

News from the European ME Alliance



European ME Alliance member Germany Fatigatio e.V. held its first International ME/CFS Conference in Dortmund 24-25 September 2010. It was attended by about 150 delegates and it was fascinating to see how attitudes of some in the audience changed once they had been presented with information from international experts such as Dr Judy Mikovits. It is very important that experts in various countries get to meet and discuss their research to find common ground and make sure further research is done on similar patient groups as the definition of ME has been allowed to be watered down by the CDC. EMEA also held its meeting in Dortmund and Dr Judy Mikovits was in attendance to give an overview of the first XMRV workshop held in Bethesda. More details and photographs [click here](#) - from Fatigatio's web site at www.fatigatio.de or via emailing info@fatigatio.de.

New ME Research Symposium

Bond University, in collaboration with Alison Hunter Memorial Foundation is hosting an International Science Symposium for Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) in December 2010.

The Symposium, to be held within the Population Health and Neuroimmunology Unit (PHANU), brings together a number of national and international specialist scientists working in the field of ME/ CFS.

Invest in ME will be sponsoring a biomedical researcher to attend the conference as part of our plans to establish an examination and research facility for ME in the UK.

MLV-Related Viruses

Bob Courtney has supplied the following article to help explain MLV-related viruses - <http://www.investinme.org/Article-800%20MLV-Related%20Viruses.htm>

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USA CFS Advisory Committee Meeting

The USA CFS Advisory Committee (CFSAC) is a panel of eleven people who meet several times a year over a three day period and the recent CFSAC meetings held on 12-14 October 2010 have been broadcast over the web.

The previous CFSAC meeting held last year, after the Science paper linking ME/CFS with XMRV was published, seemed to indicate a new era of research.

Our impressions from the first day's science meeting were very mixed. The uplifting and forward looking mood of last year's conference was gone and replaced by views and research from the past with no clear direction seemingly coming from the participants. The WPI XMRV research was hardly mentioned apart from doubts yet again being spread about contamination and Dr Chia's enteroviral research would have got no mention at all had it not been brought up by Dr Klimas in the discussions that followed on from the presentations.

This year the committee completed its three-day meeting by endorsing two recommendations for HHS, one of which was to add the "ME" to the committee's title (CFS).

It is difficult to understand why we are still talking about correct diagnosis and how to get there when we have the Canadian Clinical Guidelines to help in making that correct diagnosis. These are consensus criteria which involved clinicians who have diagnosed thousands of ME patients and have seen patients from outbreaks of the disease. The experience of these clinicians needs to be used to teach other doctors to diagnose correctly. Dr Nancy Klimas showed clear biomarkers and new research should build on those and move on with times.

Corridor gossip was casting doubts about the patients in the Science study having been infected with injections they had been given over the years as treatment. This is something which cannot be levelled at UK patients as they certainly do not have any access to experimental treatments so there should be no fear of contamination from treatments in the UK cohort, a study of which is being prepared for publication. It also seems that some researchers do not know what kind of patients they are studying. To get progress researchers need to work closely with clinicians to understand the illness they are supposed to be studying and to be able to formulate a meaningful hypothesis.

The name change suggestion to ME/CFS again provides a mixed message. Whilst accepting that we need to move away from the CFS term by using ME in the name it was also suggested that ME can stand for either myalgic encephalomyelitis or myalgic encephalopathy - an unfortunate twist and a completely wrong message.

We have been here before.

Whilst a move away from CFS might be a good thing, using myalgic encephalopathy does no good for people with ME or their families and will not help future research or help raise awareness. This debate has been performed in the past. The view has been put forward that encephalomyelitis does not accurately describe the disease - even though the WHO code is encephalomyelitis and there is convincing evidence of inflammation. Those pushing the term of encephalopathy may well have other motives rather than the good of people with ME as Dr Bruce Carruthers principal author of the Canadian Guidelines has suggested in the past - click here <http://www.investinme.org/Article%2010-Encephalopathy.htm>.

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ME stands for myalgic encephalomyelitis - the official name. The name myalgic encephalopathy does not exist and, when there is no consensus on what new name should be used, it is pointless to muddy the waters by introducing another temporary name which has no clear or credible backing.

The second day of the CFSAC heard patient testimony. Pat Fero provided some of this and gave her pdf document to Invest in ME for publication. This document - **Inadequate National Institutes of Health funding for New Chronic Fatigue Syndrome Grants** follows the gathering of evidence from requests under the freedom of information act. This is available as a pdf - <http://www.investinme.org/IIME%20Campaigning-NIH-CFSAC-2010-10-01.htm>.

This paper shows clearly how little public funding has been spent on an illness which affects so many. And how similar is this to what has happened in the UK?

Permanent Blood Donation Ban

Our letters to the Department of Health and to the Chief Medical Officer regarding the dangers to the public from ME people donating blood seem to have helped change their minds. Previously the CMO had stated to our earlier letters that, in the UK, people diagnosed with CFS/ME are excluded from donating blood while they are "unwell" and "have symptoms". As we stated in our last newsletter "the UK Blood Services Standing Advisory Committee for Transfusion Transmitted Infections decided it was premature to make any change to the above in regard to the XMRV retrovirus (despite Australia, Canada and New Zealand banning outright blood donations), but that the situation would be closely monitored as new evidence became available from the UK and from Europe. Hopefully the WPI/IiME UK studies may help focus minds."

The NHS Blood and Transplant agency has issued a press release regarding the lifetime ban of blood and transplant donations from people diagnosed with ME/CFS. This will be implemented from 1st November 2010.

Details of this are available from the NHS Blood and Transplant and The National Blood Service websites (www.nhsbt.nhs.uk and www.blood.co.uk).

This news was published by major media outlets on 8 October 2010 and the reason for this ban was given as not to harm the ME patient's health as ME is a relapsing condition. The press briefing states that -

"However, as ME/CFS is a condition where people can relapse and become ill again, donor selection guidelines are being changed as a precaution to protect the donor's safety by ensuring the condition is not made worse by donating blood."

There are many diseases of unknown causes but they are not on the banned diseases list.

Is the retrovirus research having an effect?

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Our correspondence with the CMO pointed out inconsistencies in the previous advice. Why isn't the medical profession questioning the so called Wessely school of thought on ME. It is after all doctors who diagnose people. When ME patients provide evidence of biomedical research into ME it is often dismissed yet these same doctors seem to accept, against all realms of common sense, the reasoning of the behaviouralists and psychiatrists.

Invest in ME have written to the Blood and Transplant Agency asking why, in their press release, they chose not to reference the Lo et al. paper from NIH/FDA published by PNAS in May - yet conveniently refer to the negative studies which were published in much lower impact publications.

Our letter states -

... We wondered why your press release did not mention the Lo et al. paper from the NIH/FDA
[<http://www.pnas.org/content/107/36/15874.abstract?sid=30cc5eaa-5902-4097-b2ba-f436ae4eae7b>] published by PNAS in May 25, 2010?

The Impact Factor rating is used as a guide to the relative importance of a journal within its field.

Therefore the publication by PNAS is far greater than the publications that published the negative studies to which your press release refer so it would be appropriate to reference this important paper from the two big US federal agencies in this context too and not just the negative study from the CDC.

It is also interesting that the main concern according to this press release is the protection of ME patients' health when NICE and NHS Plus itself recommend CBT (Cognitive Behaviour Therapy) with the aim of "cognitive restructuring of unhelpful beliefs and assumptions" and GET (Graded Exercise Therapy) as the only effective treatments for ME/CFS.

Is the blood service not at all concerned about the possible contamination of the blood banks with a new gamma retrovirus that has been associated with ME/CFS by two very high impact publications, The Science Magazine and PNAS?

The reason for banning ME(CFS) patients from donating blood in New Zealand, Australia and Canada (and the recommendation in USA) is due to the risk of contamination of the blood supply with a retrovirus.

We also wondered why there was suddenly such concern about the ME patients' health status when NICE and NHS Plus guidance recommend CBT and GET as effective treatments for ME/CFS and proscribe any biomedical treatments, as shown in this clip -

"Cognitive behavioural therapy and graded exercise therapy have been shown to be effective in restoring the ability to work in those who are currently absent from work."

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http://www.nhsplus.nhs.uk/providers/images/library/files/guidelines/CFS_guideline.pdf

The spin on the blood donation ban for people with ME is just that. There would, of course, be no reason to initiate a life time ban on a segment of the population if it were to protect the donor's health.

Why would this exclude people who have had ME and "recovered"?

Yet again the establishment hides the true reasons for the blood ban even though it is glaringly obvious that something very unpleasant is being hidden.

All ME patients and their carers should know that the reason for banning blood donations from ME patients is to protect (albeit belatedly) the blood banks in this country - at best as a precaution against infecting people with a virus/viruses implicated in causing ME, perhaps more likely to avoid the litigation of which we have warned the CMO.

Eventually the full story will be heard.

In the meantime we shall be enquiring as to whether this ban applies to organ donation as well.

The Impact Factor and Research

The Impact factor scale - http://en.wikipedia.org/wiki/Impact_factor

ME Business Studies - 1

Whilst the UK authorities now believe it is unsafe for people with ME to donate blood, and are admitting this fact by placing the lifetime ban on donations from ME patients, so the establishment continues to act as though nothing had happened and continue false trials and even celebrate a quarter century of failure and misinformation.

Despite the need to prohibit people with ME from donating blood due to the possibility of contamination of blood stocks via a viral agent from people with ME there are still senseless studies being carried out.

Yet another study which is examining the Lightning Process business by Dr Esther Crawley has been given funding and ethical approval despite the underlying theme of this "training programme" which states that people have to ignore their symptoms. How strange that this study can go ahead, using children, when it is clear that the patients' health is not of paramount importance. The study protocol is available here [<http://www.bristol.ac.uk/ccah/research/childrencomplexhealthneeds/chronic-fatigue/smilestudydocuments/smprotv6final.pdf>].

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Here are just a few observations from the study protocol.

This study uses school attendance as an outcome measure. We know from experience that school attendance itself means little as children may spend all their energy in getting to school and not learn anything. What is the purpose of education? Is it important that children, however sick, just sit in a class room to boost statistics by ticking the attendance sheet or is it important that children are given the opportunity to learn in a way suitable to their illness?

Questionnaires are not valid as outcome measures as the whole idea behind LP is to teach participants to stop 'doing ME' and they are told to say during the course to say they do not 'have' ME but they are 'doing' ME. If the participants were MS or cancer patients would they be told the same i.e. stop doing the disease and one's symptoms and the disease disappear?

Children are taught to lie about their reality. ("The language used by young people will be discussed and in some cases challenged.") This goes against all the common sense of listening to the child and believing in them.

External observers are listed as AYME whose medical adviser, Dr Esther Crawley, is the principal investigator of the trial - a conflict of interest?

The independent observers in the room might be influenced by the NLP/hypnosis techniques used and therefore their objectivity may be influenced. How is this scientific? LP business practices hire PR companies to promote their businesses whenever there is discussion in the media about a biomedical research study such as the recent study from Dundee University which found biochemical abnormalities in children with ME [<http://archpedi.ama-assn.org/cgi/content/abstract/164/9/817>]. They waste no time in trying to get case studies promoted on the back of legitimate research. One can only hope that the children and young people and their carers think carefully before committing themselves to clinical trials like this.

It must be confusing for the participants of this trial when they know by now that they are never allowed to donate blood because it might affect their health but the LP trial they take part in tells them there is nothing wrong with them, that their bodies are just thinking they are ill so they must stop the vicious cycle, the adrenaline loop. Why can't they donate blood if they have been successful in stopping the vicious cycle and cured themselves of ME? No doubt we will soon learn of an explanation to this from the LP practitioners as the earnings from vulnerable people are boosted by fickle media coverage.

The involvement of a supposed children's ME charity in this farcical study is shameful.

ME Business Studies -2

Normally we wouldn't highlight anything or anyone whom we feel is irrelevant for ME patients and their carers. Here is an exception. Even with a ban on donating blood for ME patients, extensive biomedical research showing the organic nature of the illness and more and more doctors and researchers shaking off the misinformation of the past - still we see the establishment continuing to act as though nothing had happened.

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Now Barts celebrates their view of a CFS/ME "service" - celebrating their own 25 year anniversary by hosting a conference consisting of presentations from, amongst others, Simon Wessely, Esther Crawley, Peter White and Trudi Chalder ("What makes therapy work").

A look at their program

(http://www.manchestercfsme.nhs.uk/document_uploads/Conferences_Training/PROGRAMME_lmdt29112010.pdf) shows everything that is wrong with the way this organisation, and their supporters, treat this disease and the patients who have it. With the government spending review continuing perhaps this particular conference might well be seen to provide proof of one organisation which could happily be included in the spending cuts - with a clear benefit to the public.

Click here for further reading

[Magical Medicine - click here](#)

[Documented Involvement of Viruses in ME/CFS - click here](#)

[Why ME Does Not Belong to the MUS Category article - click here](#)

Knowledge or Belief

IIME may have been critical of the CMO, MRC and other establishment organisations in the past. But the criticism has been based on what we have seen. Actions will always speak louder than words.

Above we can read of funding and resources being provided to two dubious trials - the PACE trials and the Lightning process business - neither of which will benefit people with a neurological illness such as ME. One of the main criticisms we have had relates to the inconsistencies used by establishment organisations regarding ME.

To our knowledge the GMC has failed to criticise or even comment on the Lightning Therapy business training programme being used to treat patients with a neurological illness nor taking any action against those who dismiss ME as a behavioural illness and treat it accordingly, or ignore it and the possible co-morbidities associated with ME. Neither does it comment on flawed research being performed under the guise of serious science. Yet the GMC instigate the banning of a doctor who attempts to treat ME from a biomedical viewpoint - Dr Sarah Myhill (<http://www.bbc.co.uk/news/uk-wales-mid-wales-11550075>) - using the excuse supplied by GMC panel chair Dr Peter Maguire that -

"The circumstances which bring patients to your (Dr Myhill's) practice by their very nature make your patients vulnerable, notwithstanding any actual health issues."

"The panel has been extremely concerned by your possible lack of understanding of the requirements of modern day best practice, as well as a seeming lack of perception and understanding of the consequences

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of your actions."

If only the GMC would apply these same standards to those doctors and psychiatrists who routinely ignore the suffering of people with ME or treat the disease as a behavioural disorder.

Read this article from Margaret Williams -

<http://www.investinme.org/Article413%20Knowledge%20or%20Belief.htm>.

Patient Choice

Perhaps new changes being brought in by the coalition government may help people with ME. According to Secretary of State for Health Andrew Lansley -

"Patients should have choice at every stage of the journey - where they register with a GP, where they go for tests, who they see for treatment, and what care or treatment they receive from any willing provider.

"Above all, they should be able to change these choices at any stage."

See <http://www.bbc.co.uk/news/health-11566123>

It will be interesting to see if and how this will affect people with ME and their families.

PACE Trials

With the flawed and discredited PACE trials being published it is crucial that people are ready for the spin from these trials which will be put forward by organisations such as Barts, the establishment, the media and by those charities which continue to support the non-science of the psychiatrists, or who sit on the fence.

The first in a series of papers coming out from the PACE Trial has been published in the Journal of Royal Society of Medicine. [<http://shortreports.rsmjournals.com/content/1/4/28.full>].

This paper gives an idea of the patients being put forward for the PACE trials. The article shows that either GPs are incompetent in screening patients for these trials or the Oxford criteria select patients with high rate (56%) of psychiatric co-morbidities.

Jason et al. have found that the Canadian Consensus criteria select cases with less psychiatric co-morbidity and more physical functional impairment and fatigue/weakness than the Fukuda (CDC 1994) criteria let alone Oxford criteria. [Jason LA, Torres-Harding SR, Jurgens A,

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Helgerson J. Comparing the Fukuda et al. criteria and the Canadian case definition for chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome*. 2004; 12(1):37-52.

"The participants' median age was 35 years (interquartile range 29–43). One hundred and two (76%) participants were women. Seventy-six (56%) participants had a co-morbid psychiatric diagnosis, confirmed by the SCID. Of these, 42 (31%) had a major or minor depressive episode, 15 (11%) dysthymia, 47 (35%) an anxiety disorder, three (2%) obsessive compulsive disorder, eight (6%) post-traumatic stress disorder, 11 (8%) social phobia and 20 (15%) a specific phobia. Several patients had more than one co-morbid psychiatric diagnosis. At baseline, 40 (30%) participants were taking an antidepressant and three (2%) were taking St John's wort. One patient was taking both an antidepressant and St John's wort."

"Conclusions Doctors assessing patients in a chronic fatigue syndrome clinic miss psychiatric diagnoses more often than misdiagnosing them. Missed diagnoses are common. CFS clinic doctors should be trained to diagnose psychiatric disorders."

1. <http://shortreports.rsmjournals.com/content/1/4/28.full>

2. Jason LA, Torres-Harding SR, Jurgens A, Helgerson J. Comparing the Fukuda et al. criteria and the Canadian case definition for chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome*. 2004; 12(1):37-52.]

It is difficult to imagine research into any other illness choosing a patient group which was defined by such loose criteria as the Oxford criteria and renders the study unscientific and worthless. It is the equivalent of studying brain tumours and accepting everyone with a slight headache to be part of the study.

Can the PACE Trials Be Justified? - [click here](#)

NICE Guidelines

The NICE guidelines for ME are to be revisited in December to ascertain if they need to be revised.

With NICE having been taken to a Judicial Review by patients with ME and with all UK ME organisations criticising the NICE guidelines (save for those establishment charities which have accepted money from the government to support their policies) one would think it obvious that these guidelines need to be completely revised. Yet it is stated that the previous GDG members will be reviewing the guidelines.

This seems macabre. We believe the previous GDG group needs to be supplemented with new stakeholders to represent the more current views. There is little doubt that the NICE

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guidelines need to be upgraded to include results from biomedical research - something which the previous GDG failed to do.

The ME Dilemma

An interesting article by Dr Iving Spurr

"Enteroviruses: Most infections are subclinical or minor - only a few progress to serious illness. Nevertheless they are the major cause of Aseptic Meningitis, Encephalitis, Myelitis, Myositis, Myocarditis, Pancreatitis and Thyroiditis. To the astute clinical mind these are the components of ME syndrome."

- [see here](#)

UK Examination and Research Facility

Our efforts in creating an examination and research facility in the UK, based in Norwich, have continued with discussions with the university and the Norfolk PCT. We are pleased to announce that the PCT has agreed to fund examinations by an ME consultant performing biomedical examinations and diagnosis. Patients who are examined and diagnosed with neurological ME (CG) would, if they agreed, be available to go forward for the research studies. IiME and the PCT have been in discussions with an experienced ME consultant for this role with a view to building up a comprehensive service and research model for people with ME. More details are available in our informational flyer [<http://www.investinme.org/Research%20-%20ME%20Institute.htm>] which describes the proposal. We hope to have more news in the near future. IiME would like to pay tribute to the fantastic support being given to the charity and to this proposal by Dr Ian Gibson - whose staunch support for biomedical research into ME has helped influence and persuade people of the importance of this proposal.

The Norfolk PCT has also been discussing with nearby PCTs in creating a non-prescribing service in Norwich as an extension of the fatigue service currently run by the James Paget clinic - which currently operates using occupational therapists and no consultant lead. This is unrelated to Invest in ME's work.

Fundraising for Invest in ME

For those wishing to contribute to the Invest in ME Biomedical Research Fund we would like to remind everyone of 8 year old Joshua's participation in the BUPA mini south run. We feel very honoured that Joshua has decided to fundraise for Invest in ME. The run takes place on 23

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October and if you would like to support young Joshua his Everyclick fundraising page can be found here <http://www.everyclick.com/joshuaforme>

We would also like to thank Jan and her friends for organising a successful fundraising event on 5 September 2010 - see <http://www.investinme.org/IiME%20Awareness%20Events.htm>.

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.

For Christmas

Lost Voices makes an ideal Christmas gift and raises ME awareness. We are arranging for copies to be given to libraries where possible. If you would like to help see our sponsor page at <http://www.investinme.org/LostVoicesBook/IiME%20Lost%20Voices%20Sponsor%20a%20Library%20Book.htm>

Conference 2011

The 6th Invest in ME international ME/CFS biomedical research conference will be held on Friday 27th May 2011 in London. We are currently planning this conference. Any help in raising awareness of the conference to healthcare providers would be appreciated as would any sponsorship help for the conference.

More details will be available on our web site in due course.

Best Wishes

Invest in ME

Support Invest in ME - [support biomedical research](#)

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patients and their families.

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Click on the [link here](#) to get to Invest in ME's page.

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