



# Invest in ME Research

# NEWSLETTER



## May 2008 Newsletter

Welcome to Invest in ME's May 2008 newsletter.

### IN THIS ISSUE

**International ME Awareness Month**

**International ME/CFS Conference 2008**

**The Whittemore-Peterson institute**

**The HHV-6 International Symposium on  
Viral infections in CFS**

**DVD Offer**

**Short Takes on ME**

***Journal of IiME***

**Around Westminster - Questions in  
Parliament**

**and what of Sophia?**

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### International ME Awareness Month 2008

We have just a short newsletter this month. May is [ME Awareness Month](#) - an opportunity for raising awareness of ME around the country, and around the world. Earlier in the year Invest in ME attempted to initiate a coordinated, international effort for May by contacting many different groups around the world. Although we weren't successful we still hope that enough is happening in May to build on the effort by many people over many years to use every opportunity to publicise the need for more urgency being given to people with ME and their families. Another option is provided by [this link](#) from Vanessa Mitchell.

The IiME London conference fittingly comes at the end of the month to provide a wonderful finale of biomedical research from some of the leading experts on ME in the world.

And no ME Awareness Month would be complete without another attempt by IiME to get Google interested in the illness and honouring the unnecessary struggle which people with ME are enduring by making a **Google-Doodle** - [see here](#). We have put in our annual request though we doubt if our third attempt will be any more successful than previous ones.

We wish everyone organising or participating in any awareness event the best of luck and hope to see many in London on 23rd May.

Best wishes,

**All at IiME**

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## **The International ME/CFS Conference 2008 - Sub Grouping and Treatments of ME/CFS and The Journal of IiME**

We are glad that there is now more talk of the need for sub grouping of ME. This was made into our theme for the conference already last year when we were planning the event and the speakers at the conference

IiME are happy to publish the 3<sup>rd</sup> Journal of IiME during May in time for the International ME/CFS conference. Included will be a conference pull-out section.

Although our hope has been to supplement the newsletter with this publication as often as we can - at least four times a year - due to lack of funding we seem to be able to produce it only twice per year at the moment. We hope this will change and that we can eventually raise funds to print/distribute the Journal to healthcare staff and others in due course.

IiME is run by volunteers for free and we attempt always to make available everything for free, or at cost price. The Journal will remain free from our web site.

In Volume 2 Issue 1 of the Journal we hope to have contributions from Japan, Norway, Australia, Sweden, Holland, USA and Korea as well as information for delegates at the IiME conference. Our thanks go to our contributors who have provided more useful information. The Journal will be part of each delegate's conference pack at the International ME/CFS Conference and made available to all after the conference.

An extract from the Journal - concerning a potential sub group -

## Research

An academic dissertation by Jaana Renko from Tampere University, Finland entitled Bacterial DNA Signatures in Arterial inflammation (2008) found signs of past bacterial infections in arterial plaques.

Atherosclerosis develops over time starting often in childhood. Plaques develop in arterial walls resulting in narrowing of blood vessels. The plaques contain chronic inflammation and it has been thought for some time that bacteria are involved in causing the inflammation. The most identified of these bacteria are Chlamydia pneumoniae and oral bacteria.

Jaana Renko examined arterial samples from autopsies and surgeries and found high overall diversity of bacterial DNA in the atherosclerotic coronary and abdominal artery samples. Her study supports the theory that past infections increase the risk of developing atherosclerosis. It is not clear whether the bacterial findings are the cause or consequence of the illness. It may be that it is easier for bacterial DNA to stick to the damaged arterial wall. This study showed the role of inflammation and possibly infection in the role of atherosclerosis.

Chlamydia pneumoniae is implicated in the development of ME/CFS in some cases and is one of the sub groups for which further research is required.

The most common causes of death among people with ME/CFS are heart failure, cancer and suicide (Jason et al. 2006). According Jason et al. people with ME/CFS died 25 years earlier than rest of the population.

see <http://acta.uta.fi/pdf/978-951-44-7249-7.pdf>

The Journals of IiME are [available here](#).

For those delegates who are attending the conference we would like add a reminder that refreshments will be available in the morning from 08.00 to 09.00, prior to the conference start. This will allow extra networking time. The agenda is available [here](#). Also, a quiet room has been made available for delegates who need to rest.

For those still thinking of coming to the conference then you are welcome.

The speakers at the conference promise to make this a unique event providing a wealth of biomedical research that builds on the research presented over the last couple of IiME conferences.

**Dr John Chia** produced research that has confirmed much of the research organised by the John Richardson Research Group in the past. An interesting blog of Dr Allen Blaivas (<http://www.healthcentral.com/sleep-disorders/c/68/14552/fatigue/>) describes Dr Chia's work as does Health on the Net <http://www.hon.ch/News/HSN/608181.html>.

Dr Chia is also on the clinical team of the CFS Research Foundation (<http://www.cfsrf.com/index.html>).

**Dr Martin Lerner** is the former Director of Infectious Diseases at Wayne State University School of Medicine and he has been studying and analysing ME for over twenty years and has published over 10 papers since 1993 on the role of sub clinical Myocarditis in a subset of ME patients. He will be speaking on successes with long term treatment with antivirals in patients with chronic EBV and CMV infections. Dr. Lerner uses antibody tests for early antigen to CMV and EBV that are not available in most commercial laboratories; he believes that they are better for differentiating active from latent infections. Dr Lerner's work has probably received less attention than deserved in the past yet there is now more interest in the link between viral Myocarditis and ME with new studies showing HHV-6 and parvovirus B-19 to be the most common viruses found in biopsies of patients with viral Myocarditis. Both viruses are also implicated in a subset of ME.

We could go on about the work of **Dr Leonard Jason** - one of the most prolific authors in the field of ME - but we'll leave it for the London conference.

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### Who is Attending the CONFERENCE

We have at least nine countries represented at the conference - from as far away as USA and Australia.

We hope to have a fair complement of people from the media. Our aim with the conference was again to attract healthcare staff to listen to some of the leading experts on ME and allow the objective data presented to change perceptions relating to ME. As we wrote prior to our first conference just one change in the knowledge of one healthcare practitioner could be significant for one family - something which will be worth the effort.

We are pleased to write that we have delegates attending representing PCTS, GP practices, ME Clinics, Universities, Educational services and occupational therapists. We also have the Medical Research Council and the Chief Medical officer represented. And, of course, we have individuals with ME and their carers or parents - without their support we could not have made this conference a reality.

### And Who is not attending

The Department of Health will not be represented despite (as mentioned later) representations made to the government ministers to be our guests for the day.

Otherwise this year we have an eclectic mix which we hope will provide a very interesting day for all.

## The Whittemore-Peterson Institute

Annette Whittemore of the Whittemore-Peterson Institute in Nevada was recently interviewed by Cort Johnson (see <http://www.immunesupport.com/library/showarticle.cfm/ID/8800>). The WPI reflects very much the model which IiME believe needs to be set up in UK and it is just a pity that the current government and MRC strategies are not yet recognising the necessity of such an approach.

It will be fascinating to listen to the WPI's Research Director Dr Judy Mikovits at the IiME London conference to hear how the WPI will be moving on with the sub grouping of ME/CFS.

Annette was also interviewed for our Conference DVD (see later in the newsletter).

## The HHV-6 International Symposium on Viral Infections in CFS

Several of the speakers at the IiME conference will also be speaking at the International Symposium on Viruses In CHRONIC FATIGUE SYNDROME & POST-VIRAL FATIGUE in Baltimore, USA, on 22nd and 23rd June. This has been organised by the HHV-6 Foundation –

more details at <http://www.hhv-6conference.com/index.php>.

The speakers include Dr Lerner, Dr Chia, Dr Kerr from the this year's IiME conference, Dr Kenny De Meirleir and Dr Dan Peterson from last year's IiME conference, as well as Dr. Anthony Komaroff, Dr Mariko Seishima, Dr Jose Montoya, Dr Nancy Klimas, Dr Suzanne Vernon, Dr Birgitta Evengard and Dr Peter White.



## DVD Offer - CG + DVD = £15

For ME Awareness Month we've decided to add a copy of the Canadian Guidelines overview document for each order placed for the IiME 2007 or 2006 DVD. This represents a saving of over £5 for each package over normal prices.

Just order the required DVD via this link and we'll add the other documents to the shipment.

## Short Takes on ME

We are grateful to Kevin Short for supplying this document - [[read here - PDF 68 kb](#)] - which contains Basic Information on ME. It is a valuable quick reference guide to ME and we know the effort that was put into compiling it (The idea for the annual IiME International ME/CFS conferences originated from the work of Kevin and the others in Norfolk who set up the 2005 talks in Norfolk with Professor Malcolm Hooper and Dr Bruce Carruthers).

There is so much unnecessary suffering occurring in the lives of pwme and their families and at times it is unbearable. Dr Speedy brings a different view on life with ME. As he says in his Blog [<http://niceguidelines.blogspot.com/>] -

I am a Family Physician or GP as it is called in Australia or the UK. I am also an ME patient unfortunately. Bed bound that is. So at the moment I'm in private practice so to speak.

Humour and satire will sometimes show the absurdity of the situation more easily than a serious review can. Dr Speedy has provided this article to IiME - [[click here - pdf -88kb](#)] - a review of ME from a slightly different angle.

## Around Westminster - Questions in Parliament

The pressure on the government to be accountable for their policy regarding ME is being maintained by pwme and their families. Recent questions tabled in the Commons show the continuing indifference

IiME's chairman, Kathleen McCall, wrote to Mark Oaten (LibDems MP), to raise issues regarding ME -

In May we are holding our 3rd international ME/CFS conference at Birdcage Walk, Westminster and the DoH and the Secretary of State have again this year refused to attend or even send representatives, it would be good if you could mention that when you speak (in parliament).

I find this very annoying, especially when all one receives in reply to any letters written to the minister or DoH are the same old standard template letters stating that there is little knowledge of the illness.

How is it possible to ignore invites to these conferences and still maintain these untruths regarding the knowledge which currently exists and which overwhelmingly supports the case for more biomedical research into ME/CFS in order to produce proper treatments and, eventually, a cure.

The line up of speakers we have is superb and we are very fortunate that they have agreed to travel to London from the likes of the USA to speak for us.

Mark Oaten's parliamentary researcher has come back with this -

We have some responses to a few of the Parliamentary Questions we (Mark Oaten) asked.

**Mark Oaten:** To ask the SoS for Health what guidance he has recently issued on the diagnosing of myalgic encephalomyelitis.

**Ann Keen:** The National Institute for Health and Clinical Excellence has published, in August 2007, a clinical guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis.

**Mark Oaten:** To ask the SoS for Health what assessment his Department has made of the clinical causes of fibromyalgia.

**Ann Keen:** We have made no assessment of the causes of fibromyalgia.

**Mark Oaten:** To ask the SoS for Health what evaluation he has made of research on the effects of genetics on people with myalgic encephalomyelitis.

**Dawn Primarolo:** None

We are still waiting for some other responses but unfortunately these aren't all that encouraging. The last one in particular is quite abrupt.

One of IiME's friends has, in the last year, been in contact with his MP - Mr. Francis Maude (Cons.) and has forcefully described the issues facing pwme and their families. Mr Maude has eventually followed up these issues by asking the following questions in parliament -

**Mr. Maude:** To ask the Secretary of State for Health if he will establish an independent scientific committee to oversee research into myalgic encephalomyelitis/chronic fatigue syndrome. [199903]

**Ian Pearson:** I have been asked to reply.

There are currently no plans to establish an independent scientific committee to oversee research into myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). However, the Medical Research Council (MRC) is planning to set up a panel of experts from different disciplines to look more closely at the area. The panel will come from varied fields including neuroscience, immunology, toxicology and imaging, and will involve interested parties and focus on the subtypes and causes of ME/CFS.

**Mr. Maude:** To ask the Secretary of State for Health if he will take steps to ensure that Government funding for biomedical research on ME/CFS is equal to Government funding for psychological research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. [199904]

**Ian Pearson:** I have been asked to reply.

The Medical Research Council (MRC) is committed to funding scientific research into all aspects of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) including evaluations of other treatments and studies into the biological and psychological basis of the condition. The amount provided by the MRC to each type of research depends on the quality and number of proposals received.

The above confirmation from Ian Pearson that a "*panel of experts from different disciplines to look more closely at the area. The panel will come from varied fields including neuroscience, immunology, toxicology and imaging, and will involve interested parties and focus on the subtypes and causes of ME/CFS*" was discussed in last month's newsletter and we await more news on the composition of this group.

The recent Royal Society of Medicine conference on CFS (which included speakers representing purely the psychosocial view of ME) confirmed our view in the **Parallel Worlds** topic in last month's newsletter that "any research performed in collaboration with the psychiatrist lobby who have so manipulated the lives of people with ME and their families over the last decades is doomed to examining relationships between valid and proven biological markers and generic, unproven and sometimes deleterious treatments."

There cannot be any attempt at mixing these conflicting positions in the name of having a balanced view.

Why should we take such a strong view on this?

We have Dr Lerner working with antivirals for the herpes family of infections and Dr Chia investigating antivirals for enteroviruses and Dr Jonathan Kerr identifying different subsets. Yet at the RSM conference we have psychiatrists stating the same unscientific



view that NICE displayed with their recent guidelines for ME where a one size fits all approach of using CBT and GET is the main answer for treating ME. Here is one of the presenters at the RSM conference - Peter White's reported conclusion to his presentation -

..is that CFS is likely to be heterogeneous (i.e. composed of diverse elements) in nature when it comes to pathophysiology/causation whereas it is more useful to regard CFS as homogeneous (i.e. of the same kind) when considering treatments.

*and*

The term ME is best avoided as it refers to an illness with neurological signs that occurred in outbreaks some time ago - such as the one at the Royal Free Hospital

[from Dr. Charles Shepherd's summary of the RSM conference - click here](#)

When there is no mention of the neurological classification of ME at the very latest conference organised by one of the establishment's pillars of medical authority then one should be left in little doubt that events will not quickly change the injustices of the past. This makes the development of the Whittemore-Peterson Institute, and similar enterprises, all the more important for the future.

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### and what of Sophia?

A proper representation of the organic nature of ME needs to be at the front of any future research. Our thanks to Horace Reid and for allowing the following to be reposted-



**The Sophia Mirza Archive, compiled by her mother, Criona Wilson.**

**The life and early death of a severely affected ME patient.**

Hospital doctors have a wry saying that "physicians bury their mistakes - psychiatrists lock theirs up".

In a sense, Sophia Mirza defied both of these options. Her forced detention within a mental hospital was reversed within weeks. And although she died as a consequence, her voice lives on. She still bears witness against those who persecuted her.

That her voice can still be heard is due to her mother Criona Wilson who, uniquely, has published her daughter's confidential medical case notes online. With visionary foresight, Sophia tape-recorded crucial interviews between herself and her doctors, and the transcripts form part of the archive. Sophia was lucid, rational and defiant to the last.

ME patients are unfortunate with their doctors. While most other patient groups have a trusting relationship with the medical profession, far too often ME patients complain of neglect, abuse, misdiagnosis and stigma. Our patients have a visceral dislike of the psychiatric construct of ME, and for good reason. Besides the disadvantages of misdiagnosis, it forces them into a clinical environment where the validity of their opinions is routinely delegitimized, where their right to give informed consent is often not respected, and where in some cases they may be subjected to involuntary detention. These are fears which lurk in the minds of all ME patients. For Sophia Mirza they became a nightmare reality.

This online archive provides a compelling narrative of Sophia's last years. But it is a painful and frightening experience to read her case notes. For this is the kind of tragedy that has the potential to affect many other patients, and from which many of us have escaped only by good luck. The narrative has the quality of a real life drama documentary, and hopefully will raise awareness among an audience beyond the confines of the ME patient community. There are close up factual portraits of patient and family, the psychiatrist, the GP and the social worker. The ineptitude of the NHS in respect of ME degrades many patients. But the nature of the disease inflicts its own humiliations on patients and family. The grim reality of life for the severely affected is described here in unsparing detail. It required considerable moral courage for Criona to publish this archive unedited.

It is possible for good to come out of tragedy. Sally Clark, Trupti Patel and Angela Cannings suffered miscarriages of justices: but now it is much more difficult to falsely accuse bereaved young mothers of Munchausen's by Proxy. Sally Clark and Sophia Mirza were both martyrs, literally, to medical failure at institutional level. But Sally Clark's case fatally undermined "Meadow's Law". Hopefully Sophia's tragedy will have the same effect on "Wessely's Law".

Horace Reid, 1 May 2008.

Sophia's case notes were first posted online by her mother on 28 April 2008 at <http://www.sophiaandme.org.uk/> With Criona's permission, I have downloaded the files and collected them in easy to read pdf format.

Criona arranged the documents in four sections.

1. The red section gives a chronological list of 213 documents from Sophia's medical records. A large and representative selection are published online.

2. The blue section contains Social Services documentation, including the warrant to search for and remove Sophia, and the report from the independent investigating officer.

3. The purple section contains correspondence with the Attorney General's Office.

4. The fourth section, (also red) contains Criona's correspondence with the GMC in respect of six doctors.

For ease of downloading I have divided them as follows.

## **1. Sophia's medical records:**

MirzaGMC1 (7.5MB), <http://www.meactionuk.org.uk/Sophia/MirzaGMC1.pdf>

MirzaGMC2 (6.8MB), <http://www.meactionuk.org.uk/Sophia/MirzaGMC2.pdf>

MirzaGMC3 (7.4MB), <http://www.meactionuk.org.uk/Sophia/MirzaGMC3.pdf>

MirzaGMC4 (5.9MB), <http://www.meactionuk.org.uk/Sophia/MirzaGMC4.pdf>

## **2. Social Services:**

MirzaSS1 (5.5MB), <http://www.meactionuk.org.uk/Sophia/MirzaSS1.pdf>

MirzaSS2 (4.3MB), <http://www.meactionuk.org.uk/Sophia/MirzaSS2.pdf>

MirzaSS3 (7.4MB), <http://www.meactionuk.org.uk/Sophia/MirzaSS3.pdf>

## **3. Attorney General's Office:**

SophiaLeg1 (5.8MB), <http://www.meactionuk.org.uk/Sophia/SophiaLeg1.pdf>

SophiaLeg2 (5.5MB), <http://www.meactionuk.org.uk/Sophia/SophiaLeg2.pdf>

## **4. GMC Correspondence:**

MirzaDrs (6.4MB), <http://www.meactionuk.org.uk/Sophia/MirzaDrs.pdf>

We still receive comments about Sophia [[see here](#)], and most recently this from Daphna, studying to be a doctor -

"I am horrified, but not entirely surprised by the behaviour of the GPs and psychiatrists involved in this case. I am currently medical student, and I can promise you that I will never forget this case when I am a doctor. I think that the attitudes towards CFS are changing (no doubt largely thanks to Sophia and her mother), but there are still many women who are treated as mentally ill, simply because doctors cannot readily explain the causes for their disease. I send my wishes for full recovery of all the patients using [this site](#), and thank you for sharing your story."

Please help us by using Everyclick whilst surfing the web. INVEST IN ME is listed on [www.everyclick.com](http://www.everyclick.com), the search engine that helps charity. Please go to <http://www.everyclick.com/uk/invest-in-me/396708/0> to do all your searching.



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