



# NEWSLETTER

## July 2009

### IN THIS ISSUE

**International ME/CFS Conference Postscript**

**Conference DVDs**

**European ME Alliance**

**Enterovirus Foundation**

**H1N1 Flu Virus**

**Pace Trials**

**Response to E-Petition to Prime Minister**

**Response to Letter to CMO**

**Fundraising for ME**

## The International ME/CFS Conference 2009 Postscript

It was our pleasure to have Hillary Johnson as our guest in London for the Invest in ME pre-conference presentation on CDC's influence on ME research throughout the world. The presentation was impressive and shocking, telling some of the inside story of how ME has been manipulated by a government agency. This has so many parallels to the concerted campaign to misinform which has occurred in the UK over the years.

Hillary's presentation will be available on our 2009 conference DVD but she has also added it to her web site - <http://oslersweb.com>.

The conference version of the Journal of IiME has been updated to include both Dr. Daniel Peterson's and Professor Kenny De Meirleir's abstracts for the conference - as neither were available prior to the conference [<http://www.investinme.org/InfoCentre%20-%20Journal%20of%20IiME.htm>].

The Whittemore-Peterson Institute for Neuro-immune Diseases was represented with Annette Whittemore giving the conference keynote speech, showing this amazing development. Dr Dan Peterson gave a comprehensive lecture based on his 25 years of clinical experience and the solid research using being performed at the WPI. This was followed by a presentation showing the dynamics and power of science by the WPI's research director Dr Judy Mikovits. We look forward to seeing this important work being published and validated.

Professor Garth Nicolson gave a very good overall lecture on the role of chronic infections and complex illnesses. His presentation was full of information to show the difficulties researchers and clinicians are faced with when meeting this group of patients.

Professor Nyland based his lecture on two recent epidemics in Norway. This has given researchers there a chance to do follow up studies on the patients who have remained ill with ME like illness. One outbreak was due to Giardia parasite and the other due to Legionella bacterium.



# NEWSLETTER

July 2009

Dr Baumgarten showed us what can be done with public funds when politicians are supportive and patients' voice is being listened to. The importance of defining the patient base carefully using the Canadian consensus document was made clear and she confirmed the inadequacies of the NICE guidelines for diagnosis.

Dr Kerr has replicated and expanded on his previous gene expression work and he showed us his usual high quality research. His team has looked at various infections linked with ME/CFS (EBV, parvovirus, enterovirus, coxiella burnettii and chlamydia pneumoniae) and found among other things that the late phase marker for EBV (nuclear antigen IGG) varied among patients compared to normal controls with patients having lesser levels. Dr Kerr and his team have also looked at the possibility of developing a SNP (single nucleotide polymorphism) based test for the genomic subtypes.

Dr Chia showed us his excellent, solid research on enteroviruses which is confirming previous work performed in the UK. He is concentrating his efforts in finding antiviral therapy against enteroviruses. He has found Oxymatrine to be beneficial for about 53% of his patients.

Professor De Meirleir preceded his conference presentation with a press conference in London on the day before (May 28, 2009) entitled "ME: End of an Era of Medical Negation" unveiling his findings from recent research which has included examining many patients in Norway and displayed conclusions regarding the complex mechanisms of ME/CFS pathogenesis, a diagnostic test, and directions for therapeutic strategies.

A separate study by Professor De Meirleir et al. has been published In Vivo, <http://bit.ly/fqKF5>. Here they observed intestinal overgrowth of Gram positive D/L lactate-producing bacteria which are also known to produce H<sub>2</sub>S [hydrogen sulphide] in presence of certain heavy metals as a survival defence mechanism.

We have a page showing Professor Basant Puri's cutting edge presentation – [click here](#).

Also present at the conference was Marian Dix Lemle who is a science writer and has published a hypothesis on hydrogen sulphide and CFS which can be found here [http://linkinghub.elsevier.com/retrieve/pii/S0306-9877\(08\)00391-5](http://linkinghub.elsevier.com/retrieve/pii/S0306-9877(08)00391-5)

A full review of the conference will appear later – [see here](#).

---

## Conference DVD

The DVD of the conference is entering its final stages of production and we hope to have it ready for distribution over the next week. The DVD will include the conference presentations and the pre-conference presentation by Hillary Johnson. The Hooper Interviews also continue with Professor Malcolm Hooper interviewing Dr Judy Mikovits, Dr Barbara Baumgarten and Hillary Johnson.



# NEWSLETTER

July 2009



Details on ordering the DVD are here ([click here for details](#)).

---

## The European ME Alliance



At the IiME Conference in May the members of the European ME Alliance held its first AGM. The Alliance now spans eight European countries with more hopefully joining soon.

A number of initiatives were discussed as the members take forward cooperation on ME affairs. Expect more news over the next months as this European initiative gathers pace. ([www.europeanmealliance.org](http://www.europeanmealliance.org))

---

## The Enterovirus Foundation

Just a reminder that the conference Journal of IiME (Volume 3 Issue 1) contained a fascinating article on enteroviruses from Professor Steve Tracey of the newly formed Enterovirus Foundation.

[Click here](#) for the Journals page.

---

## H1N1 Influenza Virus

As we publish this newsletter we are awaiting a reply from the Chief Medical Officer as to whether he considers people with ME to be more at risk from the H1N1 strain of the flu virus, and whether Tamiflu will be immediately available if requested.



# NEWSLETTER

July 2009

IiME have written to the CMO in order to establish the position for people with ME so they can discuss with their GPs and overcome any misinformed views about the nature of ME.

Some people have contacted us saying their GPs tell them people diagnosed with ME don't belong to a risk group. The reply to our letter to the Prime Minister (see below) includes this -

**"The Department of Health classes CFS/ME as a chronic neurological condition of unknown cause/s."**

The NHS Direct website includes chronic neurological diseases among high risk groups needing preferential treatment so anyone having problems with their GP can refer to this letter.

We also asked the CMO if he recommends Tamiflu vaccination for people with ME and we'll inform you if and when we get a reply.

We thought it would be interesting to mention how the situation is for some of our colleagues in the European ME Alliance in their respective countries.

In **Belgium**, a "Flu Committee" has been established with Marc van Ranst - a virologist - as head of this committee. Unfortunately, he is linked to the university of Leuven, where ME is thought of as psychosomatic. In Belgium, the latest policy is to keep the infected people who are moderately ill at home without medication. Until recently patients were treated with viral inhibitors, but this has become too expensive. Only the elderly, babies, the chronically ill and people with impaired immunity (!) will receive medication. So a contradiction there.

The Belgian government treats ME as a psychosomatic illness without impaired immunity so the fear is that pwme will not receive any medication either. The fear is that only ME patients who are recognized as chronically ill will receive treatment.

In **Denmark**, which currently has relatively few cases, the health authorities have expressed a wish for a nationwide vaccination programme - just in case.

Denmark has no policy regarding the vaccination of ME patients but it is left to each and every single patients to choose for themselves if they want it or not.

Throughout the years in various ways ME-patients have been informed about the risks of vaccination by the knowledgeable patient groups, so most of them will be careful.

Vaccination is a free choice in Denmark, as the law says that no patient can be forced to accept a treatment. People with ME do not feel comfortable with this as some feel the health authorities will certainly try putting pressure on people and try to force them into being vaccinated. They will not, however, force sick people to accept a vaccination.

The policy for those who contract the illness is to tell them to stay at home, take TAMIFLU if prescribed, drink a lot, rest a lot and keep a high personal hygiene.

In **Spain** people are concerned because Spain has the second highest number of H1N1 cases after the UK in Europe. People with ME, are especially concerned because of hyp immunity and are likely to be more vulnerable. There are people with ME right now in Spain, who have all the signs of having Influenza A but are not being tested for it because, it is thought, the health system, which already does not want to deal with ME



# NEWSLETTER

July 2009

patients properly (there is a two and a half year waiting list to see a ME doctor), does not want an avalanche of people with ME. There is also a lack of leadership on this issue. No one wishes to talk about it or deal with the issue. Doctors in Spain are hoping that pwme will not be too severely hit, and to those who probably have it now, they advise to stay home and rest (which is the standard response for any situation)...and see.

We hope to have more in the ongoing months on the [European ME Alliance web site](#).

---

## PACE TRIALS

The following information was passed to us. The PACE Trial is a multi-million pound CFS trial being run by Peter White, Michael Sharpe and Trudie Chalder. The results of this trial are expected next year.

The protocol can be seen at:

<http://www.biomedcentral.com/1471-2377/7/6>

"Protocol for the PACE trial: A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy"

Some of the typical spin of such trials is typified by this sort of statement :

"One of the most interesting studies, carried out by Dr Floris P. de Lange and colleagues in the Netherlands, showed that cognitive behaviour therapy was associated with an increase in grey matter of the brain and this increase was associated with improved cognitive function."

This type of change (accounting for only 12%), with no ME control group to compare who did not receive these psychological therapies, could easily have happened over 8 months without a treatment, and patients could have been getting better anyway with time.

The PACE trials are funded by the Medical Research Council. We continue to consider it unacceptable that the major funding body in the UK is prepared to see world-class gene research stopped yet willingly allocates large amounts of scarce funding to research on non-curative psychosocial strategies designed to 'manage' symptoms. As the PACE trial is flawed due to non-scientific diagnostic criteria being used, these costly and meaningless trials are already destined to prove whatever is wished to be proven.

One can also read in PACE Trials newsletter #3 (yes, they feel the need for a newsletter in advance of the publication of the trials)

[\[http://www.pacetrial.org/docs/participantsnewsletter3.pdf\]](http://www.pacetrial.org/docs/participantsnewsletter3.pdf) of Peter White's view of Dr John Chia's research with CFS patients:



# NEWSLETTER

July 2009

"Dr John Chia reported his interesting case control study finding Coxsackie viral RNA in the stomachs of the large majority of patients with CFS, collected over many years. The laboratory work looked convincing, but many patients had significant gastro-intestinal symptoms and even signs, casting some doubt on the diagnoses of CFS being the correct or sole diagnosis in these patients."

It makes one wonder what signs and symptoms the PACE AND FINE trial participants have. It is a pity Professor White didn't take the opportunity of saying this directly to Dr Chia by attending the recent IiME International ME/CFS conference, right on his doorstep.

These comments tally with the Barts' submission on the draft NICE guidelines which stated that "bowel symptoms are not part of CFS/ME."!!  
(see: A selection of the points the Barts CF Service made on the draft NICE Guidelines for CFS/ME at <http://tinyurl.com/2fpjxc> or <http://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind0709A&L=CO-CURE&P=R2063&I=-3> )

To paraphrase an old US election slogan, and also one of the remarks in a presentation at the IiME London conference - "**it's an enterovirus, stupid!**".

This clearly demonstrates that the strategy of the MRC in setting up a panel of "experts" and which includes those who believe ME to be a psychological illness will be a dead end for serious science in the UK and another waste of money and time. How is it possible to mix such entirely false views of ME under the banner of biomedical research?

---

## Response to E-Petition to Prime Minister

Invest in ME responded to the recent response from the Prime Minister's office to the e-petition - [see here](#).

It is our regret that we have to show the wretched response to our request from the Department of Health (our original letter having been moved from the Prime Minister's office to the DoH without comment).

The reply ([see here](#)) ignores the questions posed by our letter, repeats many of the template answers so favoured by the Department of Health in their answers to people with ME and their families, and provides no hope of any change by this department, or this government. Our request to meet with the Prime Minister was not even considered by Mr Brown, the answer being apparently delegated to a customer services contact in the Department of Health!

We shall be responding to the Prime Minister shortly.



# NEWSLETTER

July 2009

## Response from CMO to 12th May Appeal

We have already criticised the Chief Medical Officer and the government for facilitating antivirals provision for people contracting the H1N1 flu virus yet refusing to advocate a similar approach for people with ME, where biomedical research using antivirals has shown that some patients in sub groups of ME may benefit.

However, the CMO has offered IiME the opportunity to discuss ME with his policy unit. We hope to effect this opportunity in the near future.

---

## Fundraising for IiME

Now that we have completed the conference and DVD it is our intention to make progress on raising funds for biomedical research which will enable examinations and a WPI-equivalent centre to be established in the UK. Our Biomedical Research Fund will be used for this.

Some of our friends and supporters are organising events to help us.

## Cycle Ride from London to Lands End

**Rob, Dom and Si** cycle from London to Lands End.

They are going to cycle the 300 miles from London to Cornwall on the Sunday 26th July and (hopefully) arrive in Lands End by Saturday 1st August.

All money raised will go to Invest in ME, a charity that aims to raise awareness and recognition of the disease, funding research that will bring eventual diagnosis and treatment.

A friend of Rob's from school has ME and the guys are doing this to help her and people in similar situations. If you live along the route please give them some encouragement.

Their fundraising page for this is at -

<http://fundraisers.everyclick.com/info.xq?id=1172874&fundraiser-name=Dominic-Pardoe> or

<http://tinyurl.com/kqmf7f>.

---

## The Fourth Plinth

The artist Antony Gormley's "One and Other" is a project to fill the vacant fourth plinth in London's Trafalgar Square with living people 24 hours a day for 100 days, which started on 6 July 2009.



# NEWSLETTER

July 2009

Over 16,000 people applied - Margot Lawrence was one of the lucky 2,400 to be selected to fill the plinth for an hour and she will be appearing there from **2pm to 3pm on Sunday 26 July**.

Margot Lawrence is to use one of those hours in her appeal - One and Other - Invest in ME. Margot's fundraising page is at <http://fundraisers.everyclick.com/info.xq?id=1175719&fundraiser-name=Margot-Lawrence> or <http://tinyurl.com/mdd27q>.

More on Plinth - <http://www.london.gov.uk/fourthplinth/plinth/gormley.jsp>

If you make a donation, don't forget to check the Gift Aid box if you're a UK taxpayer as then your charity can claim an extra 28% from the government!

Thank you for any support you give to these fundraising efforts.

---

## The Whittemore-Peterson Institute

Finally the Whittemore-Peterson Institute is holding its annual fundraising gala on Saturday 12 September.



The **5th Annual I Hope You Dance Gala Benefit** for The Whittemore Peterson Institute for Neuro-Immune Disease will be held on Saturday, September 12, 2009 at the Peppermill Resort Casino in Reno, NV. Ticket sales for the event will begin August 10. See here

[http://www.wpinstitute.org/help/help\\_fundraising.html](http://www.wpinstitute.org/help/help_fundraising.html)

---

Best wishes to all

***Invest in ME***

***Support Invest in ME - support biomedical research***





# NEWSLETTER

July 2009

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](mailto:info@investinme.org)

To order our plain text newsletter send an email to [info@investinme.org](mailto:info@investinme.org) and entitle your email **Plaintext Newsletter**.

To unsubscribe from this newsletter send an email to [info@investinme.org](mailto:info@investinme.org) and entitle the email **unsubscribe**.

---

<a href="#">Home</a>	<a href="#">ME Events</a>	<a href="#">Research News</a>	<a href="#">Info Centre</a>	<a href="#">ME Stories</a>	<a href="#">IiME Corner</a>	<a href="#">MEdia Corner</a>
----------------------	---------------------------	-------------------------------	-----------------------------	----------------------------	-----------------------------	------------------------------

**Support ME Awareness - <http://www.investinme.org>**

