



Invest in ME Research

NEWSLETTER



December 2008 Newsletter

Welcome to a short December IiME Newsletter.

INSIDE THIS ISSUE

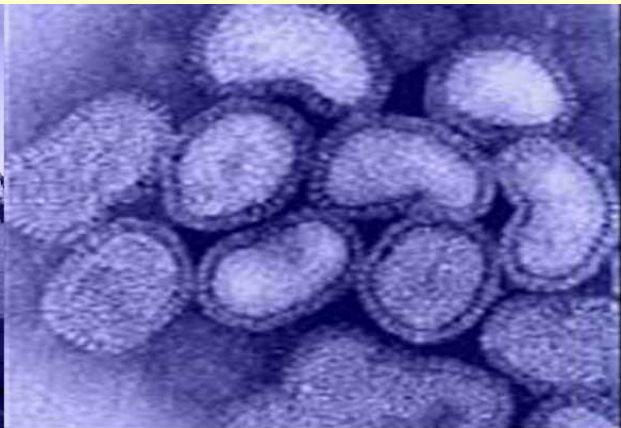
Lynn Gilderdale
Invest in ME International ME/CFS Conference 2009 News
Norway Establishes ME Centre
Dr Martin Lerner's EIPS
Quick Topics
UK MRC Panel
Christmas ideas for ME

Lynn Gilderdale

Lynn Gilderdale's tragic death should deserve more than words. Lynn suffered for seventeen years from severe ME and one can only imagine the hardships experienced by her and her family during that time. Yet her situation was like many thousands in the UK - one of the lost voices - those whose circumstances are often hidden from the rest of society.

We hope some good comes out from this tragic incident.

More needs to be done to raise awareness of the disability caused by ME and to challenge those who misinform or present ME as a benign illness.



International ME/CFS Conference 2009 - Severe ME

Our 4th annual International ME/CFS Conference 2009 on 29th May 2009, in London - management, treatment and the research of ME/CFS with a focus on severe ME.

We are delighted to announce that the Whittemore-Peterson Institute will be present at the conference in force.

IIME International ME/CFS Conference NOTE:

Mrs Annette Whittemore has honoured us by accepting our invitation to open the conference with the keynote speech and will be accompanied by another representative from WPI with updates on their major new research.

[click here for conference home page](#)

Both Annette and Dr Daniel Peterson were at our 2007 conference and gave tremendous presentations showing the vision for the WPI and this is still our most likely source of rapid progress to identifying biomarkers and countering the invalid perceptions of ME with valid science and data.

Patients who are severely affected by ME are often neglected and left without any treatment. This conference will aim to focus attention on this group of patients as, many believe, providing solutions to those severely affected by ME will likely provide a quicker path to development of treatments and cures for the different sub groups of ME.

We have now practically completed our conference agenda and are looking forward to new data being published at the conference.

For the 2009 conference we have reduced the discounted ticket price for patients and carers in order to help people to attend.

Our prices for professionals have also been reduced in the hope of getting more healthcare staff to attend and listen to the best knowledge available on management,



treatment and research into ME. We hope many groups will use our Sponsor a GP scheme and accompany local healthcare staff to the conference, thus forging or re-enforcing working relationships at the local level.

We look forward to a conference which will allow more attention to be focused on the those who are often neglected and under-represented and characterise a large proportion of ME patients.

Norway Establishes ME Centre

On 11th December Norway established an ME Centre.

The centre was opened two years after the Norwegian Knowledge Centre suggested in a report that the health services for ME patients were insufficient due to the low knowledge level of staff in Norway.

The main objective is to provide patients a proper diagnosis - something which Dr Barbara Baumgarten (head of the centre) says eludes many patients who go for years without a definite diagnosis with many having given up on getting any help.

She states that ME consists of many symptoms and that it is important that the patient is treated by specialists who are most relevant in relation to their condition.

A multi-disciplinary team at Ullevål's University Hospital will take care of and follow up these patients.

ME affects between 8000 - 15000 people in Norway.

Norway again is leading the way - something not unrecognised by the psychiatric lobby in Norway. This lobby is fighting the biomedical view of ME and resembles, and works with, their UK equivalents. The Norwegian ME Association has been playing an important part in the setup of this centre.

For more details of the Norwegian ME Centre [click here](#).



IiME International ME/CFS Conference NOTE:

Dr. Baumgarten will be presenting her team's work in this unique European centre at the Invest in ME International ME/CFS Conference in London on 29th May 2009.

[click here for conference home page](#)

Dr Martin Lerner's Energy Index Points Score

At our conference in May Dr Martin Lerner not only provided unique data in his impressive presentation but he also discussed his Energy Index Points Score Table which is an easy way for healthcare staff to monitor a patient's capability levels thus helping avoid over-exertion and monitoring of progress. Dr Lerner's presentation can be seen on the conference DVD.

Dr Lerner has given us permission to display this on the IiME web site - [click here](#).

More information is available from Dr Lerner's site at

<http://www.treatmentcenterforcfs.com/http://www.treatmentcenterforcfs.com/>

Quick Topics

'Lost Voices' - The ME Book Project

'Lost Voices' - The ME Book Project



Invest in ME's Book Project - 'Lost Voices' - is now at the printers and we are hopeful of the distribution beginning by the end of the year.

Already the book has been purchased in eight countries - from USA to Australia. We hope that finally the lost voices are going to be heard.

The Lost Voices home page - [click here](#).

Journal of IiME

The latest version was published recently and is available, for free, via this link - [click here](#).

Countess of Mar Group

We have added our input to the second meeting of the group of ME organisations brought together by the Countess of Mar - [click here](#).

Section 64 Grants and IiME

Section 64 grants are provided by the UK government's Secretary of State for Health to organisations who agree to support government health policies.

Any ME charity which applies for and accepts these grants would also have to accept the NICE guidelines and could not then oppose them or support the Judicial Review into NICE.

IiME have neither taken nor applied for such grants and have no intention of doing so.

For those who pay subscriptions to any ME organisation it might be worth asking if that organisation has received money from the government in exchange for supporting NICE and CBT and GET as the main treatments being enforced for ME.

More information can be found at the Department of Health web site here -

<http://tinyurl.com/52b2kn><http://tinyurl.com/52b2kn>

and those organisations receiving grants during recent years can be seen in the pdf files which are downloadable from that web site.

[See also the latest ***Journal of IiME*** for articles regarding NICE]

Closed Minds

Despite the UK National Institute of Clinical Excellence (NICE) being taken to court by ME patents in February 2009 the UK government is now planning on directing GPs in the UK to abide by NICE guidelines or face being disciplined [see

<http://www.pulsetoday.co.uk/story.asp?sectioncode=23&storycode=4121395&c=2>].

"GPs will have to prove they follow NICE guidelines or face the possibility of suspension, prosecution or the closure of their practice, the Government's new health and social care regulator has warned.

Baroness Young, chair of the Care Quality Commission, revealed that guidance from NICE would become legally enforceable from 2009/10, with doctors to face tough annual checks on their compliance."

By dictating how doctors are to treat their patients, especially based on guidelines which are being challenged by patients, the UK government is interfering with people's lives and placing their health at risk.

It is relevant to consider what Dr Bruce Carruthers wrote in his article in the latest Journal of IiME [[click here](#)] when he stated that there are two schools of thought on treatment - you either treat the symptoms or you try to determine what causes the symptoms.

Closed minds, ignorance and misuse of power - characteristics that have no place in medicine.

UK Medical Research Council Announces "Multi-Disciplinary" Panel

Last month we commented on the UK Medical Research Council's plans for a "multi-disciplinary" panel to be set up for ME. As predicted last June's newsletter this seems to be an attempt to marry the psychosocial view of ME with biomedical research. It remains to be seen what emphasis it places on biomedical research in comparison to the psychosocial views which the MRC have supported and funded for years. [See also the latest [*Journal of IiME*](#) articles regarding NICE]

The MRC responded to a request under the Freedom of Information Act from Suzy Chapman and provided information on the members invited to participate in their multi-disciplinary panel. The first meeting took place on Monday 15 December and the following is a list of those who have been invited to participate in the panel (the terms of reference were to be discussed at the first meeting of the panel) -

Professor Stephen Holgate	University of Southampton - Chairman
Professor Jill Belch	University of Dundee
Dr Esther Crawley	University of Bristol
Paediatrician Bath & Bristol CFS/ME NHS Paediatric Service	
Professor Philip Cowen	University of Oxford
[Professor of Psychopharmacology and MRC Clinical Scientist at the University of Oxford. His research and clinical interests are in the biochemistry and treatment of mood disorders, and particularly the pharmacological management of resistant depression]	
Professor Malcolm Jackson -	University of Liverpool
[Head, Division of Metabolic and Cellular Medicine, School of Clinical Sciences]	
Dr Jonathan Kerr	St George's University of London
Professor Ian Kimber - [Professor and Chair of Toxicology, UK Medical Research Council (MRC) Training and Career Development Board, Special Advisor to the MRC on Industrial Liaison]	University of Manchester
Professor Hugh Perry -	University of Southampton
[School of Biological Sciences, Professor of Experimental Neuropathology and Director of Research: Acute brain injury, Neurological disease]	
Dr Derek Pheby	National CFS/ME Observatory
Professor Anthony Pinching	Penninsula [sic] Medical School
Dr Charles Shepherd	MEA
Sir Peter Spencer	AfME
Professor Peter White [Senior lecturer and honorary consultant in psychological medicine. Specialty: Liaison psychiatry]	Bart's and the London School of Medicine and Dentistry

The MRC advised that "The members of the panel will be appointed by invitation, and membership will include leading experts in a number of fields including neuroscience, immunology, toxicology, imaging, psychology and psychiatry and will involve other interested parties".

The MRC state that there are currently no representatives of "other interested parties" who have an involvement with this panel. It was not made clear on what basis the invitations were made to those "interested parties" already included in the panel.

The line-up is somewhat predictable, and worrying in that it includes far too many who are known for their psychosocial bias in relation to ME or who advocate or support the use of CBT and GET as primary treatments for ME.

If the objective of forming this panel is to encourage new researchers into the field then what has caused this change of policy from the MRC when they have for years rejected high-quality biomedical research proposals and only funded research based on the behavioural view of the illness?

The IiME 2008 conference categorically established that there were distinct sub groups of ME and that research into these sub groups was the logical way forward. It was also clear from the conference that a one-size fits all approach was a fallacious and deleterious way of treating ME.

It is difficult to see how this panel could work for the benefit of people with ME and their families when the members of the panel maintain such opposing views of the illness. Maybe members of those charities whom the MRC have chosen to invite to this panel could ask their elected representatives to ensure that correct diagnostic criteria will be used for any future research projects funded by the MRC (i.e. the Canadian Guidelines). Otherwise statements from this panel stating that they are interested in encouraging more research into ME will be based on a charade and will have no real value.

Maybe the MRC will finally participate in the IiME International ME/CFS conference and attend in force.

...and finally - for Christmas

We have a Christmas page of ideas to help support ME - [click here](#).

We would like to thank all of our supporters who have helped us during the year. Your help has been invaluable. We hope all IiME supporters and readers will be able to summon optimism for the New year in the hope that progress is on the way.

As we mentioned in the Journal IiME looks forward to the New Year with a new book, a new European alliance being forged and a new conference displaying progress in the treatment and research into ME.

Happy Christmas to all,

Invest in ME

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

Please support us - support biomedical research.

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