

Invest in ME Newsletter - May 2012

(available in pdf form here)

Invest in ME Newsletter



Welcome to Invest in ME's May 2012 newsletter

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Welcome to the Invest in ME May 2012 newsletter.

7th Invest in ME International ME/CFS Conference 2012

The 7th Invest in ME annual biomedical research conference in London on 1st June is attracting delegates from sixteen countries. We are especially pleased that delegates are coming from countries and organisations whom we hope will be working in collaboration in the future with us and our colleagues in the European ME Alliance. It is upon this base of contacts that we see future progress being made.

The IiME "corridor conference" meeting which we organised last year before the 2011 conference - a round table discussion between international researchers - began cooperation and discussions. We wish to build on this (see later news item).

We have added another presenter to the line-up. We welcome Professor Maria Fitzgerald from University College London who will be presenting an overview of chronic pain. We have also revised the conference programme - [click here](#).

We welcome Professor Bruce Carruthers as our guest. Professor Carruthers was author of both the Canadian Consensus Criteria as well as the latest International Consensus Criteria for ME.

Simmaron Research have also agreed to sponsor a student to the conference.

More information about the conference and how to book can be found here - [click here](#).

Please contact us if you want us to send you flyers and posters to distribute or you can download them - [click here](#)

Conference DVD Offer

We have again decided to fund a DVD for this year's conference. During May we have an early bird offer for the DVD. All orders and payments for the DVD during May will be able to take advantage of this offer. The conference DVD will be available for £11 (UK only - European and other countries please see web site).

More details - [click here](#).

Conference Agenda

Our conference line-up has been amended slightly and is available [click here](#).

This year we are planning on allowing more discussions after each block of presentations. This will provide delegates with the possibility to ask more questions of and receive more answers from the appropriate presenters at the time of the presentation - rather than at the end of the meeting.

Announcement

The Alison Hunter Memorial Foundation (Australia) and Invest in ME (UK) are working closely together to develop an extensive international collaboration of distinguished scientists and clinicians for biomedical research into ME.

More information concerning this work will be discussed at the 7th Invest in ME International ME/CFS Conference in London.

To make rapid and worthwhile progress for the benefit of ME patients and their families we need to take bold measures, break new ground - not tread old water and force action, not just talk. We hope these current initiatives will facilitate real change. (more information).

Let's Do It For ME

IiME are pleased to see a number of fundraisers setting up JustGiving pages to raise funds for biomedical research into ME. The events range from marathon running to screen-free weekends and demonstrate the imagination and determination of people with ME and their carers.

We have had several marathon runners in the Brighton marathon and the Paris marathon. Runners Peter, 10 year old Teigan, Paul, Susie and Dave all have completed their runs and did fantastically well. Laura who was injured and had to withdraw from the Brighton marathon yet still raised funds for IiME and is hoping to run next year.

In May we have Scott Handcock taking part in Edinburgh marathon and Toby is running the Bristol marathon in September.

The Big Sleep initiated by Julia Cottam is taking place in May during ME Awareness week 6-12 May.

Website - <http://www.thebigsleepforme.com/>

Facebook <https://www.facebook.com/TheBigSleepForMe>

The positivity of the LDIFME campaign is helping us in getting much needed awareness among the wider public whilst raising funds at the same time.

Healthy supporters want to take part in positive and fun things to help those too ill to do much themselves. Positive campaigning makes a difference!



ME Awareness Month

The BIG Cause - IiME's slogan for raising awareness and funding for biomedical research into ME.

The BIG Cause highlights the need for a strategy of biomedical research into ME to be funded and implemented.



Posters available in black or white.

The IIME Biomedical Research Fund for the proposed examination and research facility has now reached £39,000. More information - [click here](#)

ME Information Packs

IIME have packs available which can be distributed to GPs and healthcare organisations and the media. The information packs are at different levels of information - the larger packs containing conference DVDs. Although we won't have funds to distribute these everywhere we are willing to provide them where necessary.

Professional Conscience

The recent decision by the Leeds Chronic Fatigue Service to remove an immunologist from the service offered is typical of the current service model in the UK where no attention seems to be paid to biomedical research - [click here](#). Typically also patients themselves seem not have been consulted on this decision.

Patients and carers become experts on ME and its effects on their lives so their views and experiences need to be taken into account at every level. From experiences with other illnesses and diseases we can see that this lack of acknowledgement of patient experience/knowledge occurs elsewhere also - it is not only confined to ME.

Yet ME is one of a few diseases which seem to generate mendacious and deleterious actions from some professionals and incomprehensible ignorance from some organisations.

Some individuals and organisations may have manipulated the way in which ME is treated or perceived. But accountability needs also to be placed at the door of the government and other medical professional organisations as well [[click here](#)].

The Neurological Alliance recently criticised the government - "People with neurological conditions feel 'thoroughly betrayed' by the Government, the Neurological Alliance representing 72 charities in the UK have said today (30 April). The Association of British Neurologists has also commented on the Government's 'missed opportunity' to improve neurology services for millions of people in England. Faced with damning criticism by two of its own watchdog bodies, the Public Accounts Committee and the National Audit Office, which suggested that billions of pounds of NHS and taxpayers' money is being wasted on inappropriate, untargeted and unscrutinised spending, one would have thought the Government would take strong measures to right the wrongs that had been exposed. But a Government response issued this morning makes clear that the Department of Health (DH) has completely ignored calls for a 'Neurology Tsar' to help develop a strategy to deliver better services. They have also refused to put sufficient and fair measures or strategies in place to ensure that the NHS and others are effectively meeting the needs of people with neurological conditions. Press Release" [click here](#).

ME has been recognised as a neurological illness by the WHO since 1969 Yet most neurologists refuse to see ME patients and their professional organisations show no interest in defending this group of patients? Individual doctors defending the rights of ME patients do not receive the backing from their respective professional organisations and often end up being prosecuted themselves.

We hope that the work to educate healthcare and academic institutions (see our announcement above) will help change this.

Sadly we have recently had to witness the effects of the professionals not listening to patients with reports of several untimely deaths due to complications with ME.

Some are well publicised and reported such as the passing away of Emily Collingridge (30) [[click here](#)], Lois Owen (34) and Victoria Webster (18). But there are many others whose deaths go unreported and away from public knowledge.

These patients have had to endure years and years of suffering without any meaningful help. We need to change this. Even if there are no cures at the moment ME patients need at least to be treated with respect and dignity. Even now, as this newsletter is published, the Danish Board of Health is attempting to section a severely ill ME patient as they perceive ME to be a mental health illness and are seemingly ignoring the wishes of the family/patient as well as the information being provided to them by EMEA-Denmark member ME Foregning. The 23-year old woman is totally bed-bound and light and sound intolerant and too weak to talk. Yet she is being threatened by psychiatrists with forcible removal from her family. The family has been repeatedly informed by Danish doctors that they do not recognise the diagnosis of ME. That such a situation is occurring in any modern European country tells the story of organisations and individuals who have failed the weakest in society.

Those who continue to be responsible for the inappropriate way that ME has been treated and portrayed over the years might wish to consider the quote -

"Death is not the greatest loss in life. The greatest loss is what dies inside us while we live".

Rituximab Trial

Invest in ME have been provided with an article from the Norwegian ME Association Newsletter. It details the status with the work of Professor Olav Mella and Dr Øystein Fluge - *What is Happening with the Research into ME and Rituximab?* - [click here](#)

Research into Visual Problems in ME

A research team at the University of Leicester are currently investigating visual problems in those who suffer from ME. Funded by European ME Alliance member IMET the Leicester team is looking to recruit individuals/patients with ME around the Leicester area to take part in visual tests at the University. IiME have been asked to forward this information to potential volunteers.

The study is concerned with basic vision problems. Participation in this study will require 2 visits to our research labs at the University of Leicester. During these visits, patients will be asked a little about their diagnosis, their general symptoms and their symptoms specifically related to vision. Patients will also be asked to complete a number of basic visual tasks, much like those encountered at a routine eye-check at the Opticians. The findings of this work are potentially important because evidence that establishes the existence of measurable symptoms in ME will help them gain acceptance in the medical community and in wider society. They may also contribute to improved diagnostic criteria for ME/CFS that will help delineate it from other conditions.

If patients near Leicester (within about an hour of travelling distance), have a medical diagnosis of ME and think they would like to take part in the study, then contact Steve Badham by email (sb569@le.ac.uk) or see <http://www2.le.ac.uk/departments/psychology/ppl/sb569> where there is information about recruitment. The team are interested in meeting patients regardless of whether or not they think they have any visual symptoms.

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