NEWSLETTER

Welcome to Invest in ME's September 2011 newsletter

published 20/9/2011

IN THIS ISSUE

6th Invest in ME International ME/CFS Conference 2011

Let's Do It For ME - Fundraising for Biomedical Research

New International Consensus

Conference DVD

Media Hype

It's A Funny Old World

IiME Response to InnovAIT Article

IiME Response to RCPCH

Special Screenings - UK Premiere of Voices from the Shadows

A New Initiative

Burst Our Bubble

Gurli Bagnall

6th Invest in ME International ME/CFS Conference 2011

We published a summary of the conference events recently - click here.

The conference report by Dr Rosamund Vallings is published here.

After the conference the BMJ mounted a concerted effort to bolster establishment support for a number of anti-ME articles and interviews appearing in the press and other media outlets. The BMJ was invited to the 6th IiME conference in order that they could become aware of the biomedical research which they have systematically ignored for far too long. We were disappointed to see that nothing has changed at the BMJ despite having access to the leading biomedical researchers and after having been invited to discuss with them in an open forum.

IiME's have published a response to the BMJ articles.

Read more >>>

Invest in ME Newsletter for September 2011

Let's Do It For ME - Fundraising for Biomedical Research

We are proud to mention a fantastic initiative started by Jo Best, and managed by Jan Laverick and Paul Kayes to support the proposal to establish a UK centre for ME - and now supported by a tremendous group of patients and carers who are making a difference. The Let's Do It For ME campaign (LDIFME) has already raised funds for the proposed biomedical research and examination facility. The campaign has a facebook, twitter and blog site and is using EveryClick to raise funds online. Details are available from the links below.

Let's do it for ME! is a patient-driven campaign to raise awareness and vital funds for a UK centre of excellence for translational biomedical ME research, clinical assessment, diagnosis and treatment for patients, training and information for healthcare staff, based in the Norwich Research Park in the UK and aiming to work collaboratively with international biomedical researchers.

A research funding thermometer has been created to monitor the status of fundraising for the initial research project. The current figure raised for a biomedical research and examination facility will be updated weekly. We invite everyone and friends and relatives to get behind this campaign and make as many as possible people aware of the proposal as well as the fund-raising. Please help us fund biomedical research into ME.

Read more >>>

Other Fund-Raising Events for Invest in ME

A list of the current EveryClick fundraising initiatives is available using this link - click here.

The ways to help us fund biomedical research are on our Help Us page and we shall supplement these when new ideas are generated.

Read more >>>

New International Consensus

A new standard for guidelines has been published by a leading group of international researchers.

The authors discuss the clinical application of their criteria, as well as paediatric considerations and research applications. The authors conclude that they -

"believe the International Consensus Criteria will help clarify the unique signature of ME" and they state unambiguously that "individuals meeting the International Consensus Criteria have myalgic encephalomyelitis and should be removed from the Reeves empirical criteria and the National Institute for (Health and) Clinical Excellence

(NICE) criteria for chronic fatigue syndrome".

Invest in ME IiME are the UK distributors for the current Canadian Guidelines and welcome these guidelines. We have for a long time stated that we support an evolutionary development and improvement of the Canadian Guidelines. We believe this is a step in the right direction.

In the past we, together with the European ME Alliance, have discussed with our conference presenters regarding updating of the criteria. The International Consensus Criteria are welcomed and we fully support these new criteria. We shall be discussing this with the European ME Alliance members as we have agreed to use common criteria. We have discussed with Professor Jason regarding the work to "operationalise" these criteria and we hope before long that these will be the foundation of a new and consistent way forward in diagnosing ME. The IACFS/ME conference in Ottawa in September will likely have more information and developments around these criteria.

Read more >>>

Conference DVD

The conference DVD 2011 was completed and ready to distribute at the beginning of August. However, due to delays in publication of the Norwegian research we have had to delay the distribution of the DVD pending news of the publication, in order to honour a promise we gave to the researchers at the conference. We have made arrangements for delivery of the DVD discs which do not contain the Norwegian research details - and we can follow up with the distribution of the other discs when allowed. As we publish this newsletter we are waiting for an imminent publication date for the Norwegian research - research which could be ground-breaking and provide hope for a basis for more clinical trials, more funding for biomedical research and future treatments for this disease.

The DVD is available to be ordered click here.

Read more >>>

Media Hype

The recent media attempts to shore up the failure of the PACE Trial were evident after our May conference. First the BMJ and then the Lancet attempted to paint ME activists as extremists (having consistently ignored the hijacking of this disease by psychiatrists for a generation). They were joined in July and August by the establishment media in a coordinated attempt to misinform about ME. The additional participants in this seemingly coordinated spate of anti-ME patient diatribes were a number of UK newspapers.

All repeated the same alleged threats to Professor Simon Wessely - a person who has been at the centre of the attempt to portray ME as a somatoform illness and yet who now professes not to be researching ME.

These articles confirm a worrying awareness that the editors of major newspapers in the UK may not only be providing distorted information to the public, but also that this misinformation may be a coordinated attempt to enforce bogus science and doctrine on unwilling patients.

IiME, along with our European colleagues in the European ME Alliance, wrote to the Times to state our concern about the complete lack of discipline and scientific rigour in one article appearing on 6th August (click here) and Professor Malcolm Hooper wrote to the Observer about another article (click here). IiME also issued a formal complaint to the Press Complaints Commission (click here).

One can only surmise that the coordinated campaign to support Professor Wessely is connected with some new event in the planning - perhaps linked to the upcoming MRC decision of handing out portions of their tiny amount of research funding for ME. There seems to be an unacceptable level of influence being exerted on so much of the establishment and many would welcome a closer examination of the influence of certain individuals on those organisations and individuals who directly affect the way that ME is portrayed or the way in which ME research is funded.

The passivity of other psychiatrists also needs to be looked at. Why are there no psychiatrists willing to stand up to these individuals whom the ME community is understandably criticising as affecting a deleterious effect on the treatment or research into the disease?

Thomas Szasz, Professor Emeritus of Psychiatry at the State University of New York in his book (Coercion as Cure: A Critical History of Psychiatry published by Transaction, USA, 2007) -

> “I maintain that it is easy to define psychiatry. I regard psychiatry as the theory and practice of coercion."..the history of psychiatry is the story of the forcible imposition of injurious interventions (with) terrible injustices committed against (people), rationalised by hollow ‘therapeutic’ justifications."

The painting of the ME community as militants, and one of the main protagonists of the somatoform lobby as a victim, is adding insult to injury and is perhaps a sign of the establishment forces panicking when an informed and vocal patient community now begin, with the aid of online media, to question and refuse to accept healthcare based on dogma.

Read more >>>

It's A Funny Old World

A different interpretation of ME and ME patients to that which certain psychiatrists would have us believe.

Read more >>>

IiME Response to InnovAIT Article

The misinformation about ME was further publicised via the journal of the Royal College of GPs - InnovAIT. IiME sent in a letter to correct some of the misleading statements made.

Read more >>>

IiME Response to RCPCH

The RCPCH recently made a statement to NICE. In Invest in ME's view this statement is not only completely erroneous. It is also very dangerous that an organisation such as the RCPCH can state such a misguided and negligent view of this disease. Invest in ME responded.

Read more >>>

Special Screenings - UK Premiere of Voices from the Shadows

Invest in ME are pleased to announce two private screenings of the new film Voices from the Shadows. This film has been invited to screen at the prestigious Mill Valley Film Festival in USA.

The two venues for these screenings are in London and Norwich.

More details will become available and published on the web site including how to reserve places.

Read more >>>

A New Initiative

Whilst IiME attempt to initiate a strategic approach to research and treatment for ME in the UK news comes of a major development from USA.

"Chronic Fatigue Initiative is a science-based 501(c)(3) nonprofit organization fostering and supporting collaboration among the world’s leading medical research, treatment and public health organizations in understanding the causes, therapies and epidemiology of Chronic Fatigue Syndrome (CFS). Headquartered in New York City and funded by the Hutchins Family Foundation, CFI seeks to accelerate the medical community’s knowledge of CFS through research grants and collaborative processes across institutions." - click here.

We hope this initiative will lead to a longer term sea-change in the way ME is researched - something which is long overdue.

Read more >>>

Burst Our Bubble

Our Burst Our Bubble campaign was used for ME Awareness Month. But we'll continue with the theme as we try to raise awareness about ME and counter the misinformation that is being published.

The posters may be downloaded from the web site, in black or white versions.

Read more >>>

Gurli Bagnall

Gurli Bagnall was a tireless campaigner against the invasive and corrosive influence of psychiatry on healthcare, and in particular on ME. Gurli Bagnall passed away recently. Gurli published many articles destroying any myths that psychiatry has anything to offer people suffering from a neurological illness.

Read more >>>

Invest in ME Newsletter for September 2011

Best Wishes to all,

Invest in ME

Follow us on Facebook - ***click here***)

Return to Newsletter Home Page

Support the IiME proposal to Initiate a UK Centre of Excellence for ME

http://www.investinme.org/Research%20-%20ME%20Institute.htm

Fundraising for Invest in ME

Our fundraising page is here - http://www.everyclick.com/investinme/info

We have wristbands for sale to help raise awareness and fund biomedical research - http://www.investinme.org/IiME-Wristbands-support.htm

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.

Use Everyclick whilst surfing the web. INVEST IN ME is listed on ***Everyclick*** the search engine that helps charity.

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.

An easy way to help Invest in ME whilst shopping is provided by Easyfundraising.

Click on http://www.easyfundraising.org.uk/Register/?char=7353 to get to Invest in ME's page. Easyfundraising provides a FREE service where you can shop with your favourite online stores and at no extra cost raise funds for Invest in ME. You still shop directly with each retailer as you would normally, but simply by using the links from this site first, each purchase you make will generate a **cashback donation** to Invest in ME.

Contacts:

Inquiries

All inquiries to Invest in ME - info@investinme.org
Invest in ME
UK Registered Charity Nr. 1114035
PO BOX 561, Eastleigh SO50 0GQ
Support ME Awareness - Invest in ME
www.investinme.org

Support Invest in ME - support biomedical research

Home | ME Events | Research News | Info Centre | ME Stories | IiME Corner | MEdia Corner