Invest in ME
NEWSLETTER

Welcome to Invest in ME's April 2013 newsletter

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IN THIS ISSUE

IIMEC8 - Mainstreaming ME Research

IIMEC8
London
2013

Registration is still open for the 8th International ME Conference in London on Friday 31 May 2013.

Since our last newsletter we have added Professor Greg Towers from UCL to the list of speakers.

The main focus of the charity has been to improve education and raise awareness of ME and lobby for a sound strategy of biomedical research into this disease.

To this end our 2013 conference focuses on the initiatives and biomedical research which are underway to find the cause of this disease and produce biomarkers for more accurate and earlier diagnosis.

The theme around the 8th annual Invest in ME International ME Conference 2013 is Mainstreaming of ME Research - reflecting our view that research into ME has become a major area to be considered by anyone wishing to perform at the forefront of medical research need look no further than ME.

The IIMEC8 theme focuses on infection and immunity and gives a platform to the latest initiatives occurring at present in ME research.

The Medical Research Council (MRC) in the UK, the Food & Drug Administration and Centres for Disease Control and Prevention in USA have created initiatives for new biomedical research into ME. In Norway the Norwegian Health Directorate have allocated funding for biomedical research into ME following the 2011 double blind randomised clinical trial using Rituximab (Anti-CD20 monoclonal antibody) by Fluge et al (PLoS 6:10.Oct 2011) to successfully treat ME patients.

There is increasing research evidence of immune dysfunction in ME patients. Even the UK MRC states -

> "There is now preliminary evidence supporting the view that inflammatory mechanisms in the brain and spinal cord may underlie the pathophysiology of some severe disease CFS/ME phenotypes. Biobanks are now becoming available and create a unique opportunity for interrogation."

We are pleased to once again be able to showcase developments around major existing projects such as the above mentioned clinical trial using monoclonal antibody, rituximab, to treat ME patients (Haukeland University Hospital, Bergen, Norway), advances in immunology (Griffith University, Queensland, Australia) and pathogen discovery and pathogenesis (CFI, USA) and The Open Medicine Institute initiative OMI MERIT.

The charity is also planning on holding a researchers meeting the day before the main conference to encourage collaborations and the sharing of ideas and of knowledge [click here].

Details of our speakers are available here [click here].

A conference leaflet is available to download [click here] along with other conference documentation.

Previous conference information and reviews and DVD options are available at this link - [click here].

Newslet link

IiME Meeting with Dr Martin McShane

Recently Invest in ME were able to meet with Dr Martin McShane - NHS Commissioning Board Authority, Director - Domain 2- Improving the quality of life for people with Long Term Conditions). Read more via the link

Newslet link

A Tale of Two Collaboratives

Research into ME should be clear and obvious. This is not a new disease and the suffering and devastating effects of the disease on patients and their families has been chronicled for a generation.

Yet comparatively little biomedical research has been funded, no joined-up thinking has been applied to the research and the research landscape has remained bare - lacking agreed and correct diagnostic criteria, lacking adequate funding and lacking correct and rational information.

In the UK two collaborative meetings for ME research are planned.

The Alison Hunter Memorial Foundation of Australia and Invest in ME are cooperating to increase collaboration and awareness and to encourage new researchers to the field we are arranging a research meeting which brings together major researchers in order to crowd source ideas on ME research. Read more via the link

Newslet link

LET'S DO IT FOR ME

The Biomedical Research Fund, which is currently dedicated toward funding of the foundation biomedical research project in the proposal for an examinations and research facility in the UK, has now reached £89,000.

In Norway the Norwegian ME Association and The ME and You Foundation are raising funds toward a large scale rituximab trial by Drs Mella and Fluge. The Norwegian Health Directorate has already allocated some funding for this research but donations from the public can help make things happen quicker. 9 million NKr is required. More details [click here].

Many people spend vast sums of money on unproven treatments for ME, often without any improvement being gained. This is entirely understandable but the only way to get treatments that help everyone safely via public health services is to get clinical trials performed. Biomedical research into of ME leads to better patient care and better doctor patient relationships.

Funding will usually follow discoveries but it is important that charities keep raising funds for strategic initial projects and encourage researchers to stay in this field.

We continue the work on initiating other trials also.

Newslet link

New IiME Ad in London

IiME placed another ad in London Business Matters in January in order to raise awareness of ME and the charity's attempts to begin a strategy of biomedical research into ME. The full page advert in London Business Matters (magazine of the London Chamber of Commerce) was the fourth time we have advertised this.

Newslet link

ICC Guidelines

Invest in ME now have available printed copies of the International Consensus Criteria for ME - the ICC Guidelines.

These are currently available for £1 per copy plus postage and packaging.

Newslet link

Lili's Story

"The extent of this ignorance in a doctor is just frightening. The fact they they have not kept up their medical knowledge is cause for grave concern.
The carer of an M.E. loved one is like no other carer.
Not only is it imperative to learn about myalgic encephalomyelitis in order to give the specialist care required for M.E. (to avoid causing them further harm), it is also necessary to become their protector."

Read more of Diane's story - Lili

Newslet link

All Things Beautiful

This is the name given by Valerie Moody to her ME awareness event in June in Co Donegal, Ireland, on 22nd June 2013.
As she has done previously all funds raised in Sterling will be given to Invest in ME and in Euros to Tom Kindlon's Irish ME/CFS Association.
Valerie has asked IiME to encourage as many ME sufferers as possible to send her their personal story plus photo as she believes it is an important way to use our collective voice. This would also allow others to know that people with ME are not isolated to one area - that it is global problem.

If you would like to contribute to this with your story then please send in, via email if you wish, your story with a photograph. We will print these and/or send them to Valerie.

Newslet link

New Research from Georgetown U.

Increased brain white matter axial diffusivity is associated with pain, fatigue and hyperalgesia in Gulf War Illness. PLOS ONE. 2013; 8 (3): e58493

Rayhan RU, Stevens B, Adewuyi O, Timbol C, VanMeter JW, Walitt B, Baraniuk JN.

http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058493.

The paper has also been covered in the British Medical Journal (BMJ) and top newspapers in the US, NPR radio, television news, and specialty science magazines.

Rakib Rayhan will be speaking at the Invest in ME IIMEC8 conference in London in May.

Here are the links to the news articles:
BMJ : http://www.bmj.com/content/346/bmj.f1958
USA today: http://www.usatoday.com/story/news/nation/2013/03/20/research-ties-gulf-war-illness-to-brain-damage/1982817/
NBC news: http://www.nbcnews.com/id/51261109/ns/health-mens_health/t/imaging-study-may-show-brain-changes-gulf-war-illness/
CNN: http://politicalticker.blogs.cnn.com/2013/03/21/cnn-washington-am-note-20/?iref=allsearch
The Washington Post:
http://www.washingtonpost.com/newssearch/search.html?st=gulf+war+illness&submit=Submit+Query
Discover Magazine: http://blogs.discovermagazine.com/d-brief/?p=248
News Scientist: http://www.newscientist.com/article/dn23303-brain-circuits-uniquely-disrupted-in-gulf-war-syndrome.html.
Georgetown University Main home page:
http://www.georgetown.edu/news/physical-evidence-of-gulf-war-illness.html
NPR radio: http://www.npr.org/2013/03/22/175054277/scientists-search-for-gulf-war-illness-answers

Archive News items

Catch-Up January 13

Short entries from earlier in 2013

- Funding for Biomedical Research into ME
- Christine's Legacy
- The PACE Trial recovery rates
- NIH State of Knowledge Report
- Let's Do It For ME - Funding for ME Research
- Debate on Atos Work Capability Assessments Useful Links
- Call For Trials to be Reported
- Biomedical Research Collaborative Meeting - Crowdsourcing for ME
- ME Chat asked us to highlight their ME Awareness Leaflet - click here

Archive News items

Events for IiME

The current events raising money for biomedical research into ME via JustGiving are listed here. We would like to thank all those making such great efforts to support the charity and raise awareness of ME.
IiME also have a chance to win £2000 for biomedical research into ME via the Direct Debit competition for good causes. One can only vote once but we would be grateful for all votes cast via facebook - the link is here.

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Invest in ME

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Support ME Awareness - Invest in ME

www.investinme.org<>