Invest in ME

February 2014 newsletter

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IIMEC9 - 9th International ME Conference

Registration has been open since January for the 9th Invest in ME International ME Conference 2014 which will take place in Westminster, London, on 30th May 2014.

The conference has been awarded the full 6 points of CPD accreditation.

IIMEC9

Synergising Research into ME

www.investinme.org

The theme of the 2014 conference is *Synergising Research into ME*.
This reflects the move to bring together biomedical research into ME to maximise the potential to find treatments and causes.

We have recently added to our list of presenters and we welcome Professor Angela Vincent, Emeritus Professor of Neuroimmunology at the University of Oxford. Professor Vincent has vast experience in neuroimmunology and runs the Clinical Neuroimmunology service which is an international referral centre for the measurement of antibodies in neurological diseases. Her major interest is in the role of autoimmunity in neurological diseases.

Dr Amolak Bansal will also return to provide an overview of diagnosis and treatment in UK and will lead a panel to discuss diagnosis and treatments for ME. Dr Bansal is heavily involved in the research being funded by Invest in ME and is the consultant leading the CFS service at Epsom and St Helier Hospitals Trust in Surrey.
Professor Simon Carding of UEA/Institute of Food Research, who is leading the IiME/UEA gut micriobiome project, and Professor Jonas Blomberg, who has recently published research funded by our European ME Alliance colleagues at IMET, compliment the agenda.

More information about the conference is available here - http://www.investinme.eu/agenda.html

Biomedical Research into ME Colloquium - 4

Collaborations and cooperation between ME researchers, and researchers from other fields, is necessary and productive.

Prior to the conference the charity has organised the fourth Invest in ME Biomedical Research into ME Collaborative Meeting to take place on 29th May in London with experts from around the world discussing ME and current and future initiatives.

Those attending include researchers at the cutting-edge of their fields - not necessarily in ME research - who will also be able to discuss the latest biomedical research initiatives underway or planned.
This seminar has already been given the maximum CPD points by the colleges.

With researchers and physicians from nine countries attending we hope to make further progress in crowdsourcing ideas and synergise research into ME. More information here - http://www.investinme.eu/news-03.html

Possibly the 2 Most Important Research Projects for ME in the UK

We have managed with the help of our resourceful and imaginative supporters to raise funds to start our foundation research project at UEA/IFR. The UEA/IFR gut microbiota project began in October 2013. This has been an impressive achievement based on past ME fundraising attempts.

In the absence of any credible or scientific strategy being presented by those responsible for public funding of proper research into ME to find causes and treatments then patients have to find and fund their own.

There are now very good researchers and clinicians willing to do research in this area and we need to continue to influence the way forward.

See more here http://www.investinme.org/LDR%20newslet%201312-01.htm

Within this project we have also been able to sponsor an intercalating 4th year medical student at UEA to perform a one year MsC degree within this project and to work alongside the PhD student.

This allows us to increase the base of experience and research opportunity, as was envisaged with our original proposal for a centre of excellence for ME.

Another complementary project is going to look further at Autoimmunity and ME/CFS with the ME consultant who is working with UEA, Dr Amolak Bansal, to perform a detailed analysis of antibodies binding the hypothalamus. To enable this project to go ahead an additional funding has been pledged by our European ME Alliance partners the Irish ME Trust).

This is not the end of the story at all though. We continue to fund for more gut microbiota-related research which will follow on. Our JustGiving page is at http://www.justgiving.com/investinm-e and we welcome help in distributing knowledge of these crucial projects.

Rituximab clinical trial for ME

In May we set out for another project together with the Let's do it for ME team and we embarked on the objective of initiating a rituximab clinical trial, something we had announced we wished to attempt at the 2012 IIMEC7 conference.

The target of £350,000 was set to be able to initiate a trial at UCL to treat a group of ME patients with rituximab based on the promising results from Norway.

Jonathan Edwards, Emeritus Professor of Connective Tissue Medicine at UCL, has been the charity's advisor on this. Professor Edwards and Dr Jo Cambridge were behind the groundbreaking proof of concept study of rituximab in the treatment of rheumatoid arthritis, and the project has been progressing well.

After several meetings with UCL it has been decided to conduct the research in two parts.

The first part involves validating and expanding on Dr Bansal's B cell study and this is ready to start soon. The second part involves the actual clinical trial using rituximab to treat ME/CFS patients selected from the cohort taking part in the B cell study. This will start once the protocol that depends on the B cell study, funding, peer review, ethical approval and other administrative processes are in place. So far we have managed to raise £283,000 of the initial target of £350,000.

The Let's Do It For ME team have created a mascot for the project - Professor Ldifme - and the professor is now assisting the UCL team and also the UEA team conducting the gut micribota project.

You can read more of the rituximab research at our dedicated web site at this link - www.ukrituximabtrial.com

See also - **The Matrix** - http://www.ukrituximabtrial.org/IIMEUKRT%20Matrix.htm

The idea of the **Matrix** is an idea to encourage individuals, organisations, teams and companies to take a slot to aim to raise up to £1000 each. 100x £1000 events would raise £100,000 and we are pleased to see a many slots reaching their target - but many more are needed.

If you have an idea which can encourage a group, a community a business or a wealthy philanthropist and wish to take a slot then please contact us at info@investinme.org.

FAQs on the rituximab clinical trial

We receive questions from patients wishing to take part in the trial which is understandable as ME patients have so few options for treatments and they are generally willing to be part of any research initiatives.

However, the charity, as funders, can have no influence on the selection process. This will be the responsibility of the research team and consultants.

The trial will be aiming to find likely responders based on the initial B cell study. The clinical trial protocol will not be designed until results from the preliminary B cell study start to come in and the patients will be selected from a cohort of patients who took part in the initial B cell study. The consultants in charge of patient selection for both parts of this trial will be those working at the Epsom and St Helier and UCLH NHS CFS clinics. More details and answers are available on the IiME web site which has been created for the project - http://www.ukrituximabtrial.org/IIMEUKRT%20FAQ.htm

News of the project is available in the news page at http://www.ukrituximabtrial.org/IIMEUKRT%20News.htm

World Events

The Institute of Medicine (IOM) contract -a new ME/CFS definition

One of the most talked about topics recently has been the US government health services contacting the Institute of Medicine (IOM) to produce a new definition for ME/CFS.

The cost of this contract is in the region of $1million!

Over 50 ME/CFS researchers and clinicians wrote against this contract asking for adoption of the Canadian Consensus Criteria.

Invest in ME wrote to Secretary Sebelius in support of the many researchers/clinicians and patients advocates who signed up to support these professionals [http://www.investinme.org/IIME%20Statement%202013-11-01.htm].

Recordings of the public comments made by many notable and well spoken US advocates can be viewed herehttp://www.youtube.com/user/instituteofmedicine/videos.

Everyone's message was more or less the same asking for the contract to be cancelled. A British lawyer Valerie Eliot- Smith also blogs about the importance of this debate and other topical issues here - http://tinyurl.com/l9lwvl5

FDA "The Voice of the Patient ' document

This document, produced by the FDA from the meetings held on 25th April 2013, is well worth reading and keeping for future reference.

It is a series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative "The April 25 Patient-Focused Drug Development meeting gave FDA the opportunity to hear directly from patients, patient caretakers, and other patient representatives about their experiences with this debilitating condition.

The discussion focused on two key topics:

(1) disease symptoms and daily impacts that matter most to patients

and

(2) patients' perspectives on current approaches to treating CFS and ME. The questions for discussion (Appendix 1) were published in a Federal Register notice that announced the meeting."
http://www.fda.gov/downloads/ForIndustry/UserFees/PrescriptionDrugUserFee/UCM368806.pdf

IACFS/ME Conference

The IACFS/ME 11th Biennial International Research and Clinical Conference to be held in San Francisco, California, USA, March 20-23, 2014. More information here - http://www.iacfsme.org

IiME AWARENESS and FUNDING EVENTS

A special mention for our supporters. We often thank our supporters and try to convey the appreciation of so many patients and families who are not in a position to do more themselves - and so rely on the efforts of the charity and its supporters.

We are privileged to have such great support.

The Let's Do It For ME campaign also has to have special mention.

The impressive imagination and vision which has dominated this campaign to aid Invest in ME in establishing proper research at prestigious universities and increase research collaboration is only exceeded by the sheer positivity shown by those running campaigns and those taking part in them.
We must not forget the great efforts of supporters using e-bay to help the charity by selling items in aid of biomedical research.

It has been a great honour to work with people who are positive, creative, determined and show the integrity and vision which is required to overcome and overturn a generation of neglect by those responsible for treating, funding and representing ME research.

Let's do it for ME!

In a short newsletter we cannot show all of the wonderful efforts being made to support awareness and biomedical research.

There are many whose efforts are not well known but their support has helped to ensure better education about ME, more awareness of the illness and greater possibilities for biomedical research to be developed.

We thank all of our supporters for continuing to help us throughout the year. We hope you realise how much we appreciate your support.

'92 in 92' Challenge for Invest In Me

The world of ME has many hurdles - one of them being isolation for patients. It is a too infrequent an occurrence for friends of someone with ME to stay in contact, let alone actively do something to help. Many ME patients can feel isolated and abandoned by their friends and even family members.

So we are amazed at the reaction and spirit of a group of four friends who are aiming to visit all 92 English Football League Stadiums in under 92 hours in support of Invest in ME and to raise money and awareness for the Rituximab Trial.

They are doing this to help their friend who has ME.

The event begins on April 16th 2014. We are really grateful for this group of four who are doing an amazing job raising awareness before the event has even started.

Football clubs, hotels, TV companies have already shown interest in this positive way of raising awareness and funds for ME.

One can follow the news of this event here

http://92in92.blogspot.co.uk

and make donations to support the amazing event click here

The charity has had a flag especially made for the tour and this will be taken along and used for photo opportunities at all of the clubs.

The Big Sleep

Julia Cottam is once again organising The Big Sleep for ME event in May.

Julia and the team did a fabulous job last year and this annual event is growing nicely and looks to be a great event to be involved in during an ME Awareness Week from 11th to 17th May.

You can read more about the many ways to get involved here http://www.thebigsleepforme.com

Walk for ME

This is the second year that Walk for ME event is being organised and it is another great event for almost anyone to take part. The website has a gallery of last year's walks and gives easy to understand information how to get involved. Those helping Invest in ME in this event will be assured that all funds received are used for activities for biomedical research into ME.

Find out more from the website here - http://walkforme.co.uk/

Several active individual pages on Just Giving have been set up to help IiME -

Bath Marathon

Two entrants to the Bath half-marathon are raising funds for IiME

Mark Webster is the son of ME patient Isabel Webster. Mike's JustGiving page and story are at -Mark's Bath Half Marathon 2014 page

Catherine Ellicott is running also - her JustGiving page is at Cath's Bath Half Marathon 2014 page. Already Catherine has achieved an incredible total.

Our grateful thanks to Mark and Catherine on behalf of all patients and carers.

London Marathon

Stephen Cox will be the charity's first supporter running in the London marathon on 13th April.
Stephen has set up a JustGiving page - http://www.justgiving.com/Stephen-Cox4
For a small charity such as Invest in ME it has always been difficult having an entry in the London marathon as the event seems geared for those charities who can afford to buy places. So we are incredibly grateful to Stephen for breaking the mold on this.

We would welcome any support in raising awareness of ME with these marathon events.

Arctic Marathon

Marathons are no mean feat to accomplish - for anyone.

An extreme way of raising awareness of ME and much-needed funding for biomedical research into ME has now been set in motion by Mike Shepherd. Mike is taking on the North Pole Marathon.

As Mike writes on his web site -This is the challenge of a lifetime and it is the result of my daughter having ME since September 2008. I have seen firsthand how damaging ME can be to a person's life, their prospects and their family.
http://www.shepherdfitness.co.uk

Books on ME

MY A-Z OF M.E. (Myalgic Encephalomyelitis)

by Ros Lemarchand

Do you feel that no one understands you?

Do you feel alone with this illness?

Do you find it hard to express how you feel?

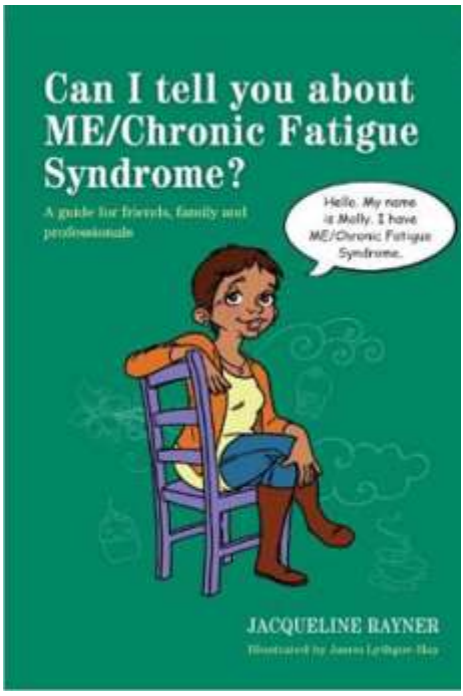
Ros Lemarchand's book of poems about life with M.E. is a must for you.

MY A-Z OF M.E. (Myalgic Encephalomyelitis) is available in both Kindle and paperback editions

http://www.amazon.co.uk/.../dp/1492735116/ref=sr_1_6

Ros also has a YouTube video about the book - click here

Can I Tell you about ME/Chronic Fatigue Syndrome?



This book by Jac Rayner.

IiME chairman Kathleen McCall has reviewed the book for the publisher and included the following comments -

"This book is very clear and easy to read.

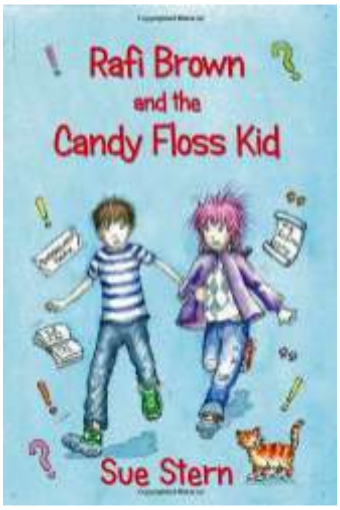
It is a great resource that can be used by ME patients and their carers to explain and inform others what it is like to be affected by ME/CFS.

Not only children but adult relatives, friends and teachers would learn a great deal from this book."

Available on Amazon at this link

Jac's book is also to be translated into Norwegian.

Rafi Brown and the Candy Floss Kid



Sue Stern has raised over £1000 by taking a MATRIX slot and donating proceeds to IiME from sales of her children's novel last year - just a year ago.

One of Sue's sons has been severely affected by M.E. and other related conditions for many years.

Her book has ISBN code 978-0-9574948-0-0.

Sue was interviewed by Kath, at Wythenshawe local radio, on her programme, 'Disability Matters'.

As a result of her suggestion, I contacted the Royal National Institute for the Blind, who are now making a large-print version of the book, and when funds allow, a Braille version!

Sue's **MATRIX** slot is here - click here

APPG for ME

ME patients are continuously denied benefits as the training given to healthcare professionals and medical assessors is not based on the biomedical basis of ME. So Invest in ME used the opportunity presented by the recent APPG for ME in UK parliament where the minister for disability Mike Pennington attended the meeting.

One of Invest in ME's questions to the minister did get through and received a response.

This, and the other questions posed by IiME which were not asked are available - click here

We encourage as many people as possible to make their views known to the minister - stating that the main barrier to work and living life to the full with ME patients is poor health and lack of proper medical care. The lack of proper medical care is due to lack of funding given to biomedical research to look into the underlying causes of ME and finding a diagnostic test.

The DWP co-funded the flawed PACE trial which sought to look into management of ME using CBT, GET or pacing without the cause of ME being known and which have shown to be a disastrous waste of money with no worthwhile result. All ministers carrying any responsibility for patients has to be made aware of these realities.

FILMS on ME

Finally noteworthy is a new film about ME which promises to raise awareness about ME at an international level in a way that may help us all change things.

With impressive funding from a KickStarter campaign *Canary in a Coal Mine* follows the lives of several remarkable people living with a Myalgic Encephalomyelitis. They are forced to leave careers they loved, abandon the dream of having children, or face the prospect of being locked away forever in their homes and bedrooms. Worse still, most doctors, and sometimes those closest to them, don't even believe they're really ill.

The film is sure to make an impact.

http://www.canaryinacoalminefilm.com/#!about/c2414xxyy

Best wishes to all

Invest in ME