



Invest in ME

March 2014 newsletter

published 22/3/2014

IN THIS ISSUE

9th Invest in ME International ME Conference 2014
Conference Agenda
IIMEC9 Conference Events
Biomedical Research Colloquium 4
Funding International Research
Fundraising Update for Our UK Rituximab Clinical Trial
ME Awareness Month
'92 in 92' Challenge for Invest in ME
Conference Questions

Research into Action



9th Invest in ME International ME Conference 2014

The 9th Invest in ME annual biomedical research conference in London on 30th May is attracting delegates from fifteen countries.

The speaker line up is now finalised with the latest addition being Professor Maureen Hanson from Cornell University, USA. Professor Hanson is a molecular

biologist who has a current gut microbiome project including ME patients and controls. She is also involved in an immune cell gene expression project and the one she is going to talk about at the conference involves markers of post-exertional malaise.

The charity is currently initiating possibly the two most important research projects for ME in the UK and the CPD-accredited IIMEC9 conference promises to be the best conference yet with biomedical research into the disease finally having become mainstream.

Another of the presenters, Professor Simon Carding - principal investigator of the Invest in ME funded IFR/UEA gut microbiota project, features in this month's Cell podcast [<http://cellreports.cell.com/>]

Gut feeling: Discussing communication between bacteria and the gut with Simon

Carding [<http://download.cell.com/images/edimages/podcasts/0227cell2014.mp3>].

In the podcast, Professor Carding discusses his recent Cell Reports paper, *A Bacterial Homolog of a Eukaryotic Inositol Phosphate Signaling Enzyme Mediates Cross-kingdom Dialog in the Mammalian Gut*. [<http://www.cell.com/cell-reports/abstract/S2211-1247%2814%2900038-2>] The Cell Reports interview segment begins at the 11:28 mark.

Synergising Research into ME is the theme of the conference and the BRMEC4 Colloquium endorses the charity's view that it is possible, and necessary, to concentrate on facilitating and enhancing biomedical research into ME to maximise the potential to find treatments and causes.

This reflects the international collaboration in biomedical research into ME which the charity believes will be at the heart of future discoveries leading to treatments for the disease.

Our thanks to the **Irish ME Trust** for once again supporting the charity and the conference.

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

Conference Agenda

The conference will open with the keynote speech by Professor Jonathan Edwards from UCL, one of the charity's advisors. We will have Dr Julian Blanco from Irsi Caixa Research Institute who will summarise the conference events from an outsider's view.

This year we will be holding a panel discussion regarding Diagnosis and Treatments within the NHS - a chance to look critically at the offerings available, at how research can influence clinical practice. This will provide delegates with the possibility for more interaction with ME consultants - Dr Amolak Bansal of

Epsom and St. Helier and Dr Saul Berkowitz from UCLH, both of whom are involved in the charity's research and who regularly see ME patients.

Almost every patient in UK (and probably elsewhere) will be seen by their GP when they get ME. Often they will be diagnosed by a GP - before, if lucky, being referred to a consultant who is knowledgeable about ME.

Whether they are referred to a consultant or not (and there are very, very few ME consultants in the UK) then the GP is likely still to play a large part in the continuing care and management of the ME patient.

So GPs will play an important role and we would ask people to help us in raising awareness of the conference amongst GPs to ensure they are aware of the biomedical research being carried out into ME.

IIMEC9 Conference Events

The charity attempts to maximise the opportunity for raising the profile of biomedical research into ME at the conference events and this year we have three other events in addition to the annual biomedical research conference which we are organising and hosting.

After the conference the [European ME Alliance](#) will be meeting to hold its AGM.

On the evening prior to the conference the charity will hold its pre-conference dinner in London and this year we are very pleased to announce that Dr Nigel Speight will be our guest speaker. Dr Speight has presented at other events organised by IiME including a past IIMEC* conference and he continues to be a source of reason and support in a world which has been corrupted by misinformation about ME. Although retired he still gives his time in support of horrendous cases of young people at risk.



The charity has been established now for nine years and we continue to have to deal with and support the terrible cases of severely ill ME patients whose treatment has suffered from misinformation, poor education about ME amongst healthcare professionals and incredible apathy from those entrusted with the responsibility for research and treatment of this disease. Too often it is children and young people who are on the receiving end of this abuse and it has often been Dr Speight who has been the last line of defence for many, as well as the last hope.

Dr Speight will also be at the conference.

Dr Speight's presentation will be on the conference DVD which the charity's trustees have decided to produce for this year's conference. During April/May we will have an early bird offer for the DVD.

Previous conference reports and the order form for past conference DVDs are available here - [click here](#).

Conference news is here - <http://www.investinme.eu/news.html>

Biomedical Research Colloquium 4

The charity's advisors, Dr Ian Gibson and Professor Jonathan Edwards, will be co-chairing the BRMEC4 Colloquium on the day before the conference. The Colloquium promises to be an extraordinary gathering of top scientists and clinicians and we feel that this is surely the future of research into ME.

International collaboration in biomedical research will lead to rapid advances in finding the cause of this disease and in development of treatments. This has been a key objective of the charity since our 2007 conference and it is heartening to find that biomedical research into ME is now squarely in the mainstream of current day research.

The CPD-accredited Colloquium is a credit to the collaboration over the years between Alison Hunter Memorial Foundation of Australia and IiME.

With researchers and physicians from nine countries attending we hope to make further progress in crowd sourcing ideas and synergise research into ME.

More information here - <http://www.investinme.eu/news-03.html>

We are especially happy to continue to attract new researchers to the field of biomedical research into ME.

Funding International Research

Dr Blanco is in the Irsi Caixa AIDS Research Institute and that institute and ASSSEM (Spanish Association of Health Professionals and Patients in Support of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome - a non-profit

organization established by people living with ME/CFS and professionals) are joining forces to research the relationship between the immune system and this illness. The objective of the study is to establish new tools for diagnosing, as well as understanding better the causes of ME/CFS and possible therapeutic directions. The planned project gives continuity to the study published last year by the same researchers which proves that there are 8 molecular alterations in people with ME/CFS which seem to be related to a faulty functioning of the immune system.

IiME have pledged funds to help this research get off the ground. More details here - [click here](#)

Invest in ME's funding opportunities for biomedical research into ME and grant policy are described on [our page here](#).

Fundraising Update for Our UK Rituximab Clinical Trial

Fundraising for a UK rituximab trial is progressing well. We have so far raised £288,000 out of our initial target of £350,000.

This is due to our wonderful supporters. It is also due to a very kind and generous donation of £25,000 toward an initial B cell study as well as a pledge of £200,000 for the actual clinical trial.

We now have permission to announce that the donation is in memory of the late Roger Hendrie who sadly passed away in March 2013.

The preliminary study to confirm and expand upon a study by Dr Amolak Bansal and colleagues that suggests that B cells may be functioning abnormally in a significant proportion of people with ME/CFS has now been through the IiME external peer review process and is just going through the final stages of the administrative process at UCL and is practically past all of the checks necessary to bring this to a start.

A tremendous effort on the part of our supporters, the lovely people providing the donation, the wonderful Let's Do It For ME spirit, our advisor Professor Jonathan Edwards and the positive, professional and proactive approach of the UCL team.

Our web site for the rituximab research is here - www.ukrituximabtrial.org

The supporters of IiME and the Let's Do It For ME team have been responsible for influencing the path of research into ME over the last two years - finally allowing it to be turned slowly in the right direction. The charity has now initiated and funded what are possibly the two most important research projects for ME in the UK - [see here](#).

In last month's newsletter we mentioned several fund raising initiatives underway.

One of these is the **Direct Debit Big Break Voting Competition**.

Direct Debit are once more giving to 100 charities and good causes in 2014. Each month from March until June they will donate £5,000 to the causes that are decided to be the most deserving. The cause that receives the highest number of votes each month will receive £2,000; the cause in 2nd place will receive £1,000; and the remaining £2,000 will be divided amongst the runners up. The number of runners up may vary each month. Voting commences on 1st March and closes at 23.59 on the last day of each month so please vote by midnight 31st March 2014.

It is easy to vote and you don't have to be UK resident (unless you text your vote with code BIG BREAK 0196 to 78866).

You can log in to vote by Facebook, Google, Twitter (only one vote per IP address) or send in a vote by post. Postal votes must be received 5 working days before the last day of the month.

All involved with Invest in ME give their time for free, and all donations go towards raising awareness of ME, improving education about ME or facilitating and funding biomedical research into ME.

Invest in ME have no salaries or large expenses - all work is voluntary.

Please help us by voting for the Invest in ME in this contest so that we can continue to progress research into this disease and bring hope to all who are affected by it and please share the links with your family, friends and support groups.

Click here to vote: www.bit.ly/Vote4InvestInME

More about The Big Break <http://www.investinme.org/IIME-Newslet-1403-01.htm> or here <http://blog.ldifme.org/2014/03/the-big-break-2014-lets-vote-for-invest.html>

And don't forget the Big Sleep again initiated by Julia Cottam during ME Awareness Month of 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!

Thanks to all our supporters and congratulations.



ME Awareness Month

The BIG Cause - IiME's slogan for raising awareness for biomedical research into ME. We continue to use posters from last year - available from the web site - [click here](#)

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

SUPPORT ME AWARENESS

The
BIG CAUSE

Building a future for research into ME

- ME is a neurological disease
- Over 60 outbreaks of ME have been recorded worldwide since 1934
- ME is 3 times more prevalent than HIV/AIDS – it is twice as prevalent as MS
- 25% of ME patients are severely affected - housebound, bedbound
- 25,000 patients are young children
- ME is the largest cause of long term sickness absences from school
- ME does not discriminate, anyone can be affected
- There is no centre of excellence in the UK that treats and researches ME as a physical illness
- UK Charity Invest in ME wants to change this with a strategy of biomedical research

Small Charity
BIG Cause
Support ME Awareness
Invest in ME
www.investinme.org

Please support our proposal for an examination & research facility for ME in the UK
- <http://www.investinme.org/research.html>

Let the Science Do the Talking

Invest in ME
Charity Nr. 1114035 www.investinme.org
Email: info@investinme.org



Posters available in black or white and can be used at any time.

'92 in 92' Challenge for Invest in ME

The 92 team are raising awareness and vital funds for biomedical research into ME by visiting all 92 FA football clubs in 92 hours.

The team has already gained pledges from half of all the clubs and continue to raise valuable awareness of ME on Twitter and across the country.

A flag and a flyer have been produced for the tour.

The event begins on April 16th 2014.

ITV Anglia will be with the team at Norwich City's Carrow Road for an interview and Talksport Radio has also expressed an interest in interviewing the team during the event.

So far

- **Bristol 24/7** have asked for a feature on the event for their website on the event
- **Coventry Telegraph** have featured the event and possibly sending a photographer to the ground
- **Examiner Huddersfield** are happy to feature the event
- **MK News**: Happy to feature our event
- **Plymouth Herald**: Sending a reporter and photographer to the ground to meet us
- **Rochdale Online**: Featured on their website <http://www.rochdaleonline.co.uk/news-features/2/news-headlines/85673/92-english-football-grounds-in-92-hours>
- **Rotherham Advertiser**: Happy to feature our event
- **Shropshire Star**: Happy to feature our event
- **South Trinity Mirror**: Happy to feature our event
- **Southampton Daily Echo**: Happy to feature our event
- **Bradford Telegraph and Argus**: Featured our event in their paper (04.03.14) and website (link to follow), sending photographer to the ground to meet the team

and there are more - see the latest on the support via the blog.

Please encourage your local media to get in touch with Mike or IiME. 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 on Facebook (www.facebook.com/92forME) and on the blog <http://www.92in92.blogspot.co.uk/> and Twitter (@92forME).

Donations to support the amazing event can be made at this link [click here](#).



Conference Questions

Finally, an offer to those who are not able to get to the conference. Besides the early bird offer of the DVD of the conference (above) we also will try to pose questions that people may have to the presenters.

If you have a question you would like one or other of the presenters to answer then, providing there is time and the question is relevant, then we will attempt to gain an answer. Please use the form in the link to send us a question.

Please keep this short as time at the conference is limited. And please keep the question relevant.

We cannot promise to have the question put to any speaker but we shall try our best - [click here](#).

Invest in ME

[Go to Newsletter Home Page](#)

Invest in ME

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Support ME Awareness - <http://www.investinme.org>

Best wishes to all

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