



Invest in ME

August 2014 newsletter

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Invest in ME Research - Let's Do Research

"Possibly the two most important research projects for ME in the UK

IIMEC9 - Synergising Research into ME



The IIMEC9 conference and Biomedical Research into ME Colloquium (BRMEC4) were the most successful yet. Synergising Research into ME was the theme and title of the conference.

With our conference and our full day research meeting on the day before the conference we could bring together different aspects of researching this disease in the hope that, by combining ideas and experiences of biomedical research into ME and collaborating in future

research, we will enhance education and the effectiveness of research efforts. It was interesting to see a number of different meetings being spawned from the colloquium and the later pre-conference dinner.

One top international researcher wrote after the conference to us – "It was a great meeting and thank you for keeping me included in it. I am inspired even at the progress since last year, though I know we need to move light-years faster to make this change the unfortunate reality for so many patients."

A conference report has been written by Dr Ros Vallings - [click here](#). We believe a number of promising initiatives have occurred from these meetings.

[Conference Journal](#)

IIMEC9 Conference DVD

The IIMEC9 conference DVD is available. The 4 disc 400 minute DVD set contains all lectures and pre conference speech by Dr Nigel Speight. The DVD is region 0 PAL version and plays on computers and DVD players worldwide.

UK orders cost £14, Europe £15.50, outside Europe £17. 400 minutes of education and CPD points may be claimed by healthcare professionals viewing this DVD.

The DVD can be ordered via this link - [click here](#).

[Read More](#)

IiME BRMEC4 REPORT DOCUMENT



Prior to the conference IiME organised the 4th Biomedical Research into ME Colloquium - a research meeting which brought almost 50 biomedical researchers from nine different countries to discuss, inform, cooperate and collaborate for the future benefit of all people with ME and their families.

Most of the major initiatives concerning ME research around the world were represented at the Colloquium including those in the UK concerning IiME's UK Gut Microbiota and UK Rituximab Trial studies and the LSHTM biobank project and autonomic nervous system research at Newcastle University.

The meeting was another huge success with a number of initiatives coming from the meeting.

The researchers continued to network after the meeting with several smaller groups of collaboration occurring.

IiME have produced a report for GPs and healthcare staff showing the extent of current biomedical research into ME. The booklet includes a summary by the charity's adviser, Jonathan Edwards, Emeritus Professor of Connective Tissue Medicine at UCL and is available from IiME.

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We are happy to send it to any healthcare professional who may find it useful. Just let us know their address and we will post a copy to them. ME Support groups can also order copies to distribute to healthcare professionals in their area. All we would ask is a contribution toward postage costs.

[Read More](#)

Invest in ME/UCL Rituximab Trial



One Event Can Change Everything

The charity is pleased to announce that our initial target for the Invest in ME/UCL rituximab clinical trial has been reached. With donations and pledges the total has surpassed £350,000.

One supporter recently donated £5000. Ambleside School in Nottingham organised a sport challenge that raised an amazing £2400. There were many other events organised by Let's Do It For ME and many individual donations from so many people, many from outside UK.

Just recently, due to a generous donation of £3000, the initial target amount was reached in full. B and J (who have requested to remain anonymous) have

donated the final £3000 toward the fund.

This generous offer has taken up three slots in the MATRIX ([click here](#)) and our MATRIX fundraising page has been updated to reflect this latest wonderful gesture.

A big thank you to everyone who contributed by way of donations, publicising the fundraising or giving moral support to many fabulous fundraisers. Thank you all!

This crowd funding campaign has been an amazing effort from so many people. The list of contributors has extended around the world. This has also shown how positive and mature the ME supporters are.

This is media worthy news and it should be more widely recognised as showing what is being achieved by people with ME and their families and friends. The

innovative Let's Do It For ME campaign has inspired all of us and now there is hope for new research that will surely influence future directions.

What Next?

Although we have reached the initial target we will continue to raise funds for a contingency for the trial in case the preliminary study produces results which affect the way forward. As soon as we are in a position to announce more about this planned trial we shall do so - but the following statement demonstrates that we have come a long way in preparing for this.

Well conducted clinical trials are desperately needed for ME patients and the best evidence for a treatment so far comes from Norway and to validate this research one needs to run trials in other countries too.

We are confident that we can complement the Norwegian research by initiating the UK rituximab trial.

We continue to welcome all support for this trial and feel confident this is the correct approach. Donations to make this happen may be made via the links on the link to the right.

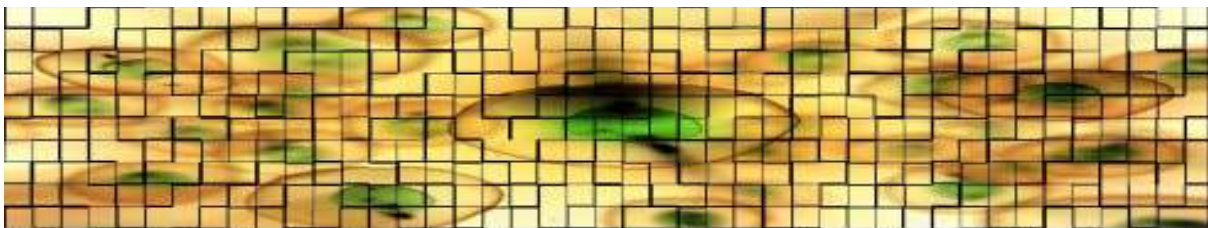
[Newslet link](#)



- A pdf document of the UK rituximab study status to download and give to healthcare professionals - <http://bit.ly/1cN4GzB>
- Two posters are available, which can be downloaded or obtained from IiME. [These are available here.](#)
- [The Funders page](#) contains those groups who have supported Invest in ME by donating.
- [The MATRIX](#) (see later article) also contains details of those supporting the trial.
- We thank all those who are supporting us in making this important clinical trial a reality.

[Rituximab Web Site](#)

The MATRIX



For our rituximab contingency fund we welcome any groups, companies, organisations and individuals who wish to contribute to the funding of the

IiME/UCL rituximab project to take a slot in the MATRIX - a unique way devised by IiME/LDIFME to raise awareness and funds for biomedical research into ME. See how the matrix is shaping up

here <http://www.ukrituximabtrial.org/IIME%20UK%20Rituximab%20Trial%20Matrix%2001.htm>

This has been a truly international collaboration with participation from Canada, USA, Australia, New Zealand, Sweden, Norway, Switzerland, Belgium, Ireland, Germany and UK.

[The MATRIX](#)

IiME UK GUT MICROBIOTA PROJECT

The UK Gut Microbiota project was also presented by Professor Simon Carding at the IIMEC9 conference in London and the research at IFR/UEA is now progressing after passing the ethical approval stages.

More information of the project can be [found here](#)

We are now raising funds for the follow-on work to this in order that the research can continue. A project is being formalised and we hope to have more news in the autumn.

The charity is also keen to extend the educational needs for ME. Funds are also sought for projects involving medical students doing a masters degree in ME related research.



The charity has updated an executive summary for MPs regarding our proposal for a UK Centre of Excellence.

This has initially been circulated to Norfolk MPs as part of a renewed attempt at progressing examinations, research and treatment in UK for people with ME.

IiME ADVISORY COMMITTEE

Following this year's research meetings IiME have decided to formalise an advisory committee of researchers to help with planning the strategy for future biomedical research.

We hope this will allow more focus on research required to find the pathomechanism of the disease. Our existing advisors Dr Ian Gibson and Professor Jonathan Edwards will be part of that panel among others.

The first meeting will take place at the end of the summer.

SEVERE ME

Anyone who was present at the IiME pre-conference dinner in London in May, or who has purchased the IIMEC9 conference DVD and listened to Dr Nigel

Speight's presentation, would be left in no doubt about the harm being done to patients around Europe from the psychosocial view of ME.

Dr Nigel Speight spoke eloquently and emotionally about **Very Severe - Why Are Patients neglected and Abused?**

We left the event wondering why Dr Speight is still needing to fire-fight against a system that allows systemic abuse of very severely ill defenceless ME patients?

It is clear that patients have very little support from the establishment so it is no wonder families choose to keep very low profiles when a family member is very severely ill.

Legal and human rights and statements from NICE or from ministers seem to matter very little when diagnosis can be changed by so-called "experts" from ME to Pervasive Refusal Syndrome, Munchausen's by Proxy or something else.

Who is responsible for this state of affairs?

There is little point in blaming doctors and nurses in general as they get trained and regulated by someone.

Diagnosis is still problematic as patients vary a lot and without careful history taking and the right kind of questioning many treatable conditions may be missed. On the one hand doctors need to be very careful before giving patients an ME diagnosis and on the other hand one has more success of treating patients successfully if the condition is recognised early.

But there is little excuse nowadays for healthcare professionals to be ignorant of current research into ME.

If the Department of Health can intervene when abuse in the NHS has been publicised in other areas then that department also should be morally bound to do so when ME patients are being neglected or mistreated.

When training and education or knowledge about ME is lacking (as even the chair of the RCGP admitted at our IIMEC8 conference in 2013), or even worse when it is misleading then it is necessary for that to be rectified by those entrusted with responsibility for maintaining healthcare standards.

We asked Dr Martin McShane these questions ourselves ([click here](#)) in our teleconference meeting with him last year. But, even when confronted by parents of a severely ill young adult (who themselves have been victims of the systemic bias and ignorance of ME), apart from empathy it seems that the establishment just does not want to know - and certainly does not want to act.

Dr Speight says he is tired of fire-fighting. Why does he have to fire-fight?

We have long stated that it was impossible to make progress if government bodies continue to act in practice as if ME is a psychosomatic or medically unexplained condition, despite assurances that they accept the WHO classification of ME as a neurological illness classified in ICD10 G93.3. No organisation acting in this way deserves to command support and should be open for public scrutiny.

It is difficult to see how government departments, healthcare services or research-funding bodies can be influenced in the correct way if two entirely different views are being presented all under the term ME.

It is precisely because of such a misinformation that doctors are allowed to continue to remain ignorant of ME; that the DoH are allowed to play games around patient organisations; that ministers and ATOS officials can attend meetings about ME but leave and do nothing afterwards; and that national

funding agencies can reject valid research proposals based on ideology and biased reviews rather than on scientific merit.

Why does Dr Speight have to fire-fight? One does not have to look far for basic answers to this question.

Dr Speight's presentation is on the IIMEC9 conference DVD - [click here](#)

Meanwhile we move things on with high-quality biomedical research. What can be stated is that without continued education and awareness campaigns by patients, advocates and organisations who have campaigned for many years for a change in strategy, and without the efforts of the biomedical researchers who have been presenting at IiME international conferences then very little progress would be made.

Certainly those organisations using public funds for research have clearly been forced into a wake-up call by patients making determined efforts to facilitate biomedical research into ME.

We have now held 9 international conferences and 4 research colloquiums - biomedical research meetings which will have nothing to do with the psychosocial view of ME but are heavily structured around sharing and cooperation and international collaboration. Yet though it is important for us who we work with - it is ultimately those whom we work for that matters. IiME is working for the benefit and future of ME patients and their families.

Christmas cards and Calendars

The LDIFME team have launched the ***Let's Get Snapping for ME*** Xmas Card Competition.

The competition is going to be run through a Competition App. This means that rather than emailing in photos entrants will just be able to go our Competition Page Entry Form and upload directly. We will still have the option to accept email entries - but this will really only be for those who have problems using the form or who are not on Facebook.

The voting will purely be done via the public vote through our Gallery Page which will open on 1st Sept.

Then Invest in ME will judge the final stage.

The link for the Competition is <http://woobox.com/b83vfy>

European ME Alliance Expands

In London in May IiME chaired the European ME Alliance AGM and were extremely pleased to expand EMEA NORDIC with member groups from Iceland and Finland.



This makes the number of countries represented in EMEA to thirteen countries.

More details [click here](#).

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[Go to Newsletter Home Page](#)

Invest in ME

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Best wishes to all

Invest in ME

Research into Action

