



# ***Invest in ME Research***

# **NEWSLETTER**



**April 2014 Newsletter**

Greetings from IIMER. Welcome to the April2014 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***

## IFR/UEA Press Releases

A great deal of publicity has been created by the recent press release surrounding Invest in ME's foundation research project at the University of East Anglia/Institute of Food Research.

This project was funded by IiME supporters and friends and is looking at the gut microbiome in ME patients. The project was envisaged by the charity and university in 2010 and the funds were raised in full last year.

The following links show the press releases -

- <http://news.ifr.ac.uk/2014/03/crowdsourcing-me-research/>
- <https://www.uea.ac.uk/mac/comm/media/press/2014/March/mefunding>
- <http://businessweekly.co.uk/academia-a-research/16754-crowd-of-me-sufferers-raises-p100k-for-key-research>
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- Daniel Vipond talks about his @Invest\_in\_ME funded research at @IFRScience & @uniofeastanglia on @BBCNorfolk 1h14m <http://www.bbc.co.uk/programmes/p01vfw22>
- IiME are now raising funds for the next phases of microbiome research. The IFR is world-leader on gut research and the Norwich Research park has extensive facilities to build a base of high-quality biomedical research into ME. Our continued efforts include other projects as spin-offs to the continuing gut microbiome research leading, we hope, to understanding the cause(s) of ME and possible developments of treatments.
- Please help us raise awareness of the new target for the research [[click here](#)].
- Invest in ME's funding opportunities for biomedical research into ME and grant policy are described on [our page here](#).

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## BRMEC4 and IIMEC9 Conference Events

A reminder of our IIMEC9 International ME Conference in London on 30th May. This CPD-accredited conference is our ninth annual biomedical research conference and this year is perhaps the strongest - with a great deal of research which is gradually coming together to make the future for ME patients and their families more promising.

The conferences have always had researchers and patients mixing and networking and working together. It is as a result of our conferences that many new initiatives have occurred - not least of which has been the initiation of possibly the two most important

research project for ME in the UK - the gut microbiome project (mentioned above) and the UK rituximab clinical trial [[click here](#)].



These projects were funded by patients, carers and friends in order to initiate proper and strategic research into this disease.

This year's conference is full of research from all continents and from top-class researchers - [the agenda is here](#).

A new addition to the conference is Dr Andy Kogelnik who returns to discuss the OMI research and contributes to the panel discussion on diagnosis and treatments for ME.



Dr Kogelnik will also be participating in the Biomedical Research into ME Colloquium 4 - our fourth research meeting bringing together scientists and clinicians from eight countries.

The IiME Colloquiums occur on the day before the conference and we are fortunate to have an impressive mix of experienced ME researchers and some from other fields.

The charity's advisors, Dr Ian Gibson and Professor Jonathan Edwards, will be co-chairing the BRMEC4 Colloquium and the range of researchers and organisations attending is a force for change regarding ME.

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Our title of the IIMEC8 conference was Mainstreaming ME Research - something that is now evident in the follow on meetings.

In order to cover the severely affected and to highlight the reasons why we feel our conferences and research meetings are required we have invited Dr Nigel Speight to present the keynote speech at our pre-conference dinner on the evening before the conference.

The terrible cases of abuse of ME patients continues - almost all of them based on the ignorance about ME which the government and those organisations responsible for researching ME have allowed to be fabricated over a generation.

Dr Speight continues to be involved in cases where lives are being directly affected by the ignorance about ME which has been allowed to be built for a generation.

**Karina Hansen**

Ignorance about ME is not, of course, confined to the UK. Karina Hansen's case in Denmark continues to cause alarm as does the apparent silence of the Danish Health minister and those who entrusted with Karina's care in the Hammel Neurocentre in Jylland.

Again IiME have written to the minister and to the Hammel Neurocentre physicians to offer help by inviting them to our conference events in London where we will facilitate meetings to help Karina [[click here](#)]. Again we have received no response.

When one offers help then common courtesy dictates that it is declined or accepted. As we have seen from the cases of how badly things have gone wrong in some of the non-ME cases in the UK NHS health staff (and ministers) are accountable - and will be held to account.

Holgate of the MRC was quoted last year as saying we are bathing in a sea of ignorance regarding ME. We agree - although we would say we have been drowning rather than bathing. It is rather disingenuous, though, of those who have been involved in controlling funding for ME research and have been aware of the lack of results from the psychosocial approach to ME to talk of ignorance.

It is organisations such as the MRC and the NIH in the USA who have been helping to fill the bath for all these years.

How else can one explain the lack of funding for biomedical research especially into causes of ME? Experienced researchers such as Professors Ron Davis and Ian Lipkin are willing to study the disease but cannot get NIH funding. Surely the often-used excuse of lack of good quality research applications does not apply here. It is obvious that there has been, and still is something profoundly wrong with the peer reviewing system regarding biomedical ME research applications within these organisations - something IiME has mentioned frequently over the years. It is vital that these organisations address this as a matter of urgency - perhaps even via parliamentary scrutiny.

The policies of these organisations seem to affect other countries also - and so we have situations like that of Karina, where blind ignorance of the effects of ME and a lack of proper research cause patients' lives to be endangered.

*It is too late to learn to swim when the water is up to your lips* says the old Danish proverb.

In the Danish parliament recently the scale of systemic ignorance was glaringly illustrated by the comments in the Parliamentary Health Committee public hearing on functional disorders.

Functional Syndromes - a euphemism for much of what has been wrong with the involvement of psychiatry in ME - was shown to be an inadequate term covering many poorly researched diseases - and Danish doctors were singled out as not having enough knowledge of the diseases that are difficult to diagnose [[click here](#) for the parliament site coverage and [click here](#) for TV2's commentary.

## German TV Programme on Severe ME

The coverage of ME by UK media is normally inaccurate and simplistic. A video from the German TV programme "Menschen - das Magazin" shows the reality of a family living with ME. It tells the story of Katharina and her two severely ill daughters, Pauline and Adele, who are

both suffering from ME [[click here](#)].

## Direct Debit Voting Competition

Thank you to everyone who voted and helped Invest in ME in the recent Big Break competition.

iIME won the top £2000 prize thanks to a lot of hard work and effort from dedicated supporters

The prize will be spent on one or more of the biomedical research projects we have - rituximab clinical trial, gut microbiota developments. We are looking to initiate other projects and are in discussion with our advisors.

This was again a great team effort.

Thank you again for all the great images, videos, music and all the other imaginative ways you used to get people voting for us.

There is no doubt we have the best supporters in the world.

The wonderful, positive spirit of the supporters we have shines through. Patients, carers and friends are making a difference.

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**Invest in ME**

**DIRECT Debit**

**The Big Break**  
Help give 100 good causes a Big Break

**Won £2000!**  
Towards biomedical research into ME

**THANK YOU**

Many thanks to everyone who participated

**'Let's do it for ME!' together**

Supporting lives in ME Charity No. 1146755  
Let's do it for ME!  
Myalgic Encephalomyelitis

Whilst we begin fundraising for further microbiome-related research our fundraising for a UK rituximab trial continues and has now passed the £291,000 mark and continues to progress well.

Our donate page carries the totals [[click here](#)].

We are also pleased to announce a donation from the [Irish ME/CFS Association](#)



This amazingly generous gesture was announced by world-renowned advocate Tom Kindlon, who is the vice-chair of the Irish ME/CFS Association. The funds will be used for biomedical research projects which are underway or being planned.

Tom was one of the first to contact IiME when we formed as an organisation and his encouragement in the early days helped enormously as we began to find our feet.

All at IiME, as well as our supporters would like to thank the members and board of the Irish ME/CFS Association for this donation.

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### **IACFSME Conference overview by Anthony Komaroff, MD**

A summary of the proceedings from the 11th International IACFS/ME Conference 'Translating Science Into Clinical Practice' San Francisco , 20-23 March 2014, can be viewed here <http://www.youtube.com/watch?v=nyyjRdbvPj0> .

### **Turn The World Blue for ME**

An imaginative scheme for raising awareness and funds for ME research has been Juliann Chown - Turn Your Body Blue for ME - [click here](#). Juliann's fundraising page is at <https://www.justgiving.com/Julieann-Chown>

A similar scheme which ties in well for this is the May 12th awareness campaign which aims to help shed light on ME by shedding light on prominent buildings for the day. IiME have joined this by agreeing to write to the administration contacts for major buildings in the UK asking them to join the world wide awareness campaign - [click here](#).



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Turning the world blue for an evening may turn a few heads to increase awareness.



## '92 in 92' Challenge for Invest in ME

The time is rapidly approaching where the 92 team begin their tour of all 92 FA football clubs.

If you or friends have the possibility then please meet the team - the planned schedule described on the blog site at <http://www.92in92.blogspot.co.uk/>

One can follow the news of this event on Facebook ([www.facebook.com/92forME](http://www.facebook.com/92forME)) and on the blog <http://www.92in92.blogspot.co.uk/> and Twitter (@92forME).



**Raising money & awareness for ME sufferers, Invest In ME & the Rituximab Trial**  
[www.92in92.blogspot.co.uk](http://www.92in92.blogspot.co.uk)

**92 Football Grounds in 92 hrs**

**Small Charity BIG Cause**  
Support ME Awareness  
Invest in ME  
[www.investinme.org](http://www.investinme.org)

[www.92in92.blogspot.co.uk](http://www.92in92.blogspot.co.uk)

[www.facebook.com/92forME](http://www.facebook.com/92forME)

[www.justgiving.com/teams/strobl](http://www.justgiving.com/teams/strobl)

**For Invest in ME ([www.investinme.org](http://www.investinme.org))**

[@92forME](https://twitter.com/92forME) [facebook.com/92forME](http://facebook.com/92forME)

**Visiting 92 English Football League Grounds in 92 hours. Starts April 16th 2014**  
**JustGiving [www.justgiving.com/teams/strobl](http://www.justgiving.com/teams/strobl) or text IIME92 £1 £2 £5 to 70070**

## One more iME supporter becomes a published author

We are pleased to announce that children's book writer Celia Loefsy's book '**The Company of Goblins**' has been accepted for publication by an independent publisher.

Celia has been supporting Invest in ME in many ways and especially by organising several supermarket collections in the Hampshire area.

Celia will be participating in the World Book Night 2014 and Lee-on-the-Solent bookshop has invited her to be one of their authors this year. The event is open to all and you are welcome to join them on Wednesday, April 23rd, 7-9pm for their annual Lee-on-the-Solent literary event to meet local authors.

The venue: The Book Shop, 142 High Street, Lee-on-the-Solent, PO13 9DD.

One can order Celia's book through [www.littleknollpress.co.uk](http://www.littleknollpress.co.uk)

To find out more about goblins visit [www.thecompanyofgoblins.com](http://www.thecompanyofgoblins.com)

[Go to Newsletter Home Page](#)

## *Invest in ME - Research*

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UK

***Support ME Awareness - Invest in ME Research***





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# One Event Can Change Everything

[www.investinme.org](http://www.investinme.org)

**One small charity – one BIG cause**  
**A rituximab clinical trial for ME**

[www.ukrituximabtrial.org](http://www.ukrituximabtrial.org)

**Myalgic Encephalomyelitis (ME) is a serious, chronic neurological disease. A UK trial of rituximab for ME is being initiated and organised by Invest in ME and University College London.**

**The charity wishes to establish a Centre of Excellence for ME in the UK.**

**Please support us and help us to help people with ME.**

**Let's Do It For ME. Let's Do Research.**

Small Charity