



Invest in ME Research

NEWSLETTER



February 2007 Newsletter

Welcome to the February 2017 newsletter.

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FROM NORWAY to NORWICH - POSTSCRIPT

The workshop to plan the UK rituximab trial took place in Norwich Research Park as planned with members of the Norwegian Haukeland University Hospital RituxME team visiting the UK research team at the end of January.

Dr Øystein Fluge, Kari Sørland and Dr Ingrid Rekeland joined with the iIMER-funded researchers, including Professors Simon Carding and Tom Wileman, Professor Angela Vincent and Dr Jo Cambridge and Fane Mensah. Others from the Norfolk and



Norwich university Hospital, Clinical Trials Unit and the local ME service attended and a very interesting and productive workshop took place. We were pleased to have Chris Armstrong present for part of the discussions. Chris has been in London working with Fane.

BBC INTERVIEWS on CENTRE of EXCELLENCE

Following the workshop the researchers transitted to Norwich to hold a public lecture on the Centre of Excellence being enhanced in Norwich and the Norwegian rituximab trials.

Over 160 had registered for the event and we had arranged for the Institute of Food Research (IFR) to film the event.



Great work by Andrew Chapple and Andy Walker from IFR have now completed the video and this is available on the IFR YouTube site here <https://youtu.be/r9k5QrdtjEU>

At the suggestion of Invest in ME Research, the BBC used the opportunity of the visit by the Norwegian team to interview Dr Fluge and Professor Carding about the rituximab trial and research and the developing UK Centre of Excellence for ME at Norwich Research Park.

IiMER also provided some suggestions for patients to be interviewed to help viewers understand the effects of ME. This is not an easy thing to do - people being interviewed give out their lives for all to see and it takes a very special courage to do this in order. Two very courageous patients, Charlotte and Rosalind, did just this.

With professional and sensitive journalism - something that has not been associated with other BBC handling of ME in the past - the BBC Look East team produced some of the best TV coverage of ME that has been seen in a long time.

The links to the BBC programmes are here -

<https://www.youtube.com/watch?v=tF3jZWVc8F8&feature=youtu.be&app=desktop>

<https://www.youtube.com/watch?v=cSmxDmy-08g>

Everyone was impressed by the Norwegian team and we are very pleased to welcome them all back in May when they participate in the [7th Invest in ME Research Biomedical Research into ME Colloquium](#).

Although Invest in ME Research has been highlighting plans to establish a Centre of Excellence for ME for some years, and although our supporters have been raising funds for the UK rituximab trial since we announced plans for that in 2013, it has suddenly

been seen by many more people to have become the reality we have known for some time.

And that is fine - *"..... a hundred acorns are sown in silence by an unnoticed breeze."*

A couple of days in Norwich to redefine ME in the media and research - [click here](#).



UK CENTRE of EXCELLENCE for ME PLANS

The ramping up of capacity and research at the UK Centre of Excellence for ME is now the objective and is underway. Five PhDs are now involved in research (at Norwich Research Park and UCL).

We hope to fund more medical students to participate in research by intercalating in their medical studies for a year.

This has proved to be extremely effective at expanding research capacity, increasing knowledge and overcoming prejudiced views about ME, which have been allowed to be built up in medical curricula by the false and misleading information caused by establishment policies and organisations over the years.

We also hope to fund a post-doc/Research Associate position to augment the research.

Our aim is to ensure that a strategy of biomedical research produces results as quickly as possible.

FAST TRACKING SOLUTIONS FOR ME

**Centre
of Excellence for ME**

investinmeresearch.org

Let's  research!

For this we need help and support - this is the best opportunity for UK research.

We invite support to raise funds and awareness for this enterprise.

[#CofEforME](#)

[#letsCresearch](#)

Our thanks to all those who have donated to the Centre of Excellence, the gut microbiota studies, the medical students and to our research fund. Also to those who have donated or pledged funds for the rituximab trial/B-cell research - including organisations and individuals from around the world - with no strings attached but just a wish to have high-quality biomedical research carried out.

The other research at the Centre - which started with the foundation project - is underway - [more details here](#).

It is good to see that more acceptance and support of the UK Centre is increasing.

But we do welcome more support - [ways to help us are here](#) or our [Big Give link here](#).

[Read more](#)

RESEARCH NEWS from FANE MENSAH

Fane Mensah is being funded by Invest in ME Research for the B-cell research at UCL with Dr Jo Cambridge [[The potential role of B cells and their products in ME/CFS Patients](#)]

This crucial work has been continuing and is augmented by a recent collaboration with Chris Armstrong from Australia. Fane and Chris met at IiMER's **#BRMEC6** Colloquium in London in 2016.

Fane has kindly produced this update - showing the importance of continuing this research and of international collaboration. And the funding given by IiMER to help with students contributing to these studies demonstrates the importance of continued fundraising attempts to maintain our support for high-quality research.



[Read More](#)

COLLOQUIUM/CONFERENCE NEWS 2017



CONFERENCE SPONSORS

We are very pleased to receive news from Norges ME Forening in Norway that their board is to sponsor the IIMEC12 Conference in London by making a donation towards costs. This is another generous gesture from EMEA colleagues who have been so supportive in the past.

Again, this year IiMER looks forward to welcoming many Norwegian friends, patients and carers to IIMEC12 conference. Already we have invited and received acceptances from nine Norwegian researchers to participate and/or present at our 7th Biomedical Research into ME Colloquium ([#BRMEC7](#)) in London - a two day closed researchers meeting that precedes the [#IIMEC12](#) public conference.

Read more [here](#)

We are also pleased to have just received a donation from our EMEA colleagues in Sweden - RME.

RME also helped us last year in this way and this year IiMER looks forward to welcoming our many Swedish friends, patients and carers to the IIMEC12 conference.

We have so far invited seven Swedish researchers to participate and/or present at our seventh [Biomedical Research into ME Colloquium](#) (BRMEC7) and twelfth International ME Conference.

The donation will be used to cover some of these costs.

[Read More](#)

COLLOQUIUM/CONFERENCE PARTICIPANTS

Invest in ME Research are very pleased to announce that Dr Beth Unger from the USA Centers for Disease Control and Prevention (CDC) will be participating in the BRMEC7 Colloquium and IIMEC12 Conference.

Dr Beth Unger has accepted our invitation to both events and this means we will have representation from the major Centres around the world, including Australian, USA and European institutes, as well as the UK Centre of Excellence in Norwich Research Park, and from major agencies such as NIH, CDC – and hopefully some others that we are awaiting to announce officially.



[Read More](#)

Along with the Norwegian Haukeland team we have invited Professor Karl Johan Tronstad also to the Colloquium. Karl was involved with the recent paper to come from Bergen - [Journal of Clinical Investigation Insight](#).

More details [here](#)



We are also extremely pleased that our invitation to the Yanan Bryceson group at Karolinska Institutet in Sweden has been accepted. The [Bryceson Group](#) studies subsets of lymphocytes, such as cytotoxic T cells and natural killer (NK) cells.

Their laboratory is based at the Center for Infectious Medicine and employs a wide range of techniques including multiparameter flow cytometry, confocal microscopy, live-cell imaging, next-generation sequencing, and biochemical techniques.

Jakob Theorell will be talking about recent ME research carried out by the group.

[Read More](#)

Early-bird registration fees are in effect currently.

Use the following links for more information -

[Register here](#)

[Agenda](#)

[Venue](#)

[News](#)



CMO VISIT

Invest in ME Research had requested a meeting with all four CMOs (England, Wales, Scotland and Northern Ireland) of the UK.

The meeting was held in January, in London, and a brief summary of the meeting has now been made.

[Read More](#)

CURRENT FUNDRAISING



We welcome new help in fundraising for our research - as well as expressing thanks to those who are, or have been fundraising.

Some of these are shown in the following links -

[Current fundraising campaigns](#)

[Previous fundraising campaigns](#)

Mike's EU Marathons



The next European marathon that Mike Harley is running - to raise funds and awareness for Invest in ME Research - is in Barcelona, Spain.

This will be number 10 out of an incredible 28 EU marathons that Mike has set as a target - [click here](#) for the charity's page on this great campaign.

Mike recently interview some Spanish ME patients ([click here](#)) - another chilling testimony to the lack of services for ME patients in Europe.

JustGiving page - <https://www.justgiving.com/fundraising/mikeseumarathons>

Mike's Blog page - <http://www.mikeseumarathons.eu/>

We hope to see Mike at the [#IIMEC12](#) conference in London in June.

[Go to Newsletter Home Page](#)

Invest in ME - Research
UK Registered Charity Nr. 1114035
PO BOX 561,
Eastleigh SO50 0GQ
UK



Support ME Awareness - Invest in ME Research

FAST TRACKING SOLUTIONS FOR ME



of Excellence for ME

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Let's  research!

Myalgic Encephalomyelitis (ME) is a serious, chronic neurological disease. UK Charity Invest in ME - Research (IMER) are establishing a Centre of Excellence for ME - a hub for research activity in Europe - enabling a strategy of high-quality biomedical research projects to follow, coordinated and collaborating with other institutes. Please support our C of E for ME. Let's Do It for ME. Let's C research into ME. See <http://www.investinme.org/research#CofEforME> #LetsCresearch @LetsDoIt4ME

Invest in ME - Research (UK charity nr. 1153730)

www.investinme.org

email: info@investinme.org