



Invest in ME Research

NEWSLETTER

October 2016 Newsletter



Welcome to the October 2016 newsletter.

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HELP US BUILD A FOUNDATION FOR BIOMEDICAL RESEARCH INTO ME

Here is a statement from Invest in ME Research concerning good news with our efforts to establish a Centre of Excellence for ME in Europe.



IiMER WINS AWARDS for ALL GRANT

to publicise Centre of Excellence for ME

Invest in ME Research is a UK charity intent on changing the landscape of research for patients with myalgic encephalomyelitis (ME) and their families.

Diagnostic tests and medical treatments can only be developed from sound scientific biomedical research.

Invest in ME Newsletter October 2016

Classified by the World Health Organisation as neurological, ME is a multi-system, multi-organ disease.

To create a base of research into ME has been the ambition of the charity since 2007.

We are therefore pleased to announce that Invest in ME Research has been awarded a Big Lottery Awards for All grant to help us publicise our proposal for a Centre of Excellence in Norwich, UK, which could form a hub of biomedical research into ME for Europe.

Link here - <http://future.cofeforme.eu/ce-bl-grant-1610.shtml>



We are very grateful to the Big Lottery for this boost.

The Big Lottery Awards for All grant to Invest in ME Research will allow us to hold an awareness event to publicise the advantages of a centre of excellence for ME in Norwich.


Thank you to all those who have donated to the charity in support of our proposal.

Link here - <http://future.cofeforme.eu/ce-bl-grant-1610.shtml>

We hope to hold an event in the coming months to show the opportunities available with this initiative.

Our microsite is currently a collection of different information collated from our website and brought together - and it will be augmented over the coming months - <http://www.cofeforme.eu>

More information is there as well as ways to help us raise funds and awareness of this venture.

Please help us publicise this venture by joining our campaign by taking  selfie, or getting others to do it, and sending it to us - details here

<http://future.cofeforme.eu/ce-Support-cofeforme.shtml>

and use our hashtags **#CofEforME** and **#letsCresearch** when tweeting

This will take a substantial effort to achieve but we feel it can be done and the rewards for people with ME would be huge.

It would be a great achievement if this could be realised during the tenth anniversary of our ambition to effect this goal.

We welcome investment in this enterprise and support from all who wish to see research into ME based on high-quality science and an urgency in all efforts to tackle this disease.

Our Big Give page is here

<https://secure.thebiggive.org.uk/donation/to/6239/9169>



The Centre of Excellence for ME would be welcome news for patients, and their families and doctors, across Europe.

Establishing such a Centre represents a very progressive step in looking for cause(s) of ME. It will facilitate and initiate new international collaborations, will consolidate and improve existing ones, and develop new research ideas, and bid for funds that would enable cooperation and sharing with joint projects being undertaken.

The Centre of Excellence will also provide a high-quality partner for those Centres of Excellence being set up or existing in USA and Australia.

The Norwich Centre of Excellence now has four PhDs working on ME - under the supervision of Professors Carding and Wileman. The fourth PhD is currently finishing his work on our foundation project ([click here](#)).

The charity also has B-cell research underway at UCL in London where our other funded PhD - Fane Mensah - is working under supervision of Dr Jo Cambridge.

The good collaboration that has been established with the researchers at Haukeland University Hospital in Bergen continues and Dr Cambridge and Dr Fluge met recently in Stockholm at a conference organised by our European ME Alliance colleagues at RME Sweden.

The collaboration between high quality biomedical researchers - one of the major themes behind Invest in ME's research strategy - has been a great success with the Norwegians expressing to us and Dr Cambridge their



gratitude for the specialised knowledge and input that has been provided to them.

The UCL team will be in the regular multi-centre status meeting in Bergen - such is the respect in which they are held, as well as continuing the good collaboration.

As we prepare for the UK rituximab trial this is good news indeed.

Fane is currently giving a poster presentation at the IACFS conference in Fort Lauderdale in Florida.

Fane has promised to tweet and send us texts from Florida once proceedings are underway.

QUADRAM INSTITUTE

Good news for the Norwich Research Park came when the BIG C donated to the new Quadram Institute in Norwich - which is where the IFR will relocate - [click here](#)

One can follow the QI progress at this link in Norwich Research Park [here](#).

REGISTRATION OPEN FOR 2017 CONFERENCE



Invest in ME Research is a founder member and Chair of the [European ME Alliance](#) (EMEA) - and EMEA recently joined the European Federation of Neurological Associations (EFNA).

An objective of Invest in ME Research is to forge international collaborations between researchers to solve this complex disease.

In its first year in 2006, one of the first steps taken by Invest in ME Research to achieving this was to establish an annual international conference (IIMEC) bringing together patients, biomedical researchers, medical and other professionals.

Added to the mix of IIMEC events is an international biomedical research colloquium (BRMEC) which facilitates discussions and collaborations.

We continue in 2017 with **#BRMEC7** and **#IIMEC11**

Plans are well underway for the 2017 Colloquium and Conference events and it is good to see not only confirmed speakers for both events but also very good early bookings for the Conference.



We are also very pleased to witness that the wonderful sense of collaboration experienced at the BRMEC6 Colloquium this year in London already seems to be continuing for the BRMEC7 Colloquium on 31st May - 1st June 2017. Our 2017 conference events are now open for registration.

The Biomedical Research into ME Colloquium ([#BRMEC7](#)) will take place over two days on 31st May - 1st June 2017. This is a closed researchers' meeting focused on international collaboration on research into ME.

The public International ME Conference ([#IIMEC12](#)) will be held on 2nd June 2017.

More details of these events are available at <http://www.investinme.eu>

Update from LIDFME

We would like to thank all our supporters for their continuing support - and a huge thanks to the **Lets' Do It For ME** team for their unstinting efforts. This is a community to be proud of.

The LDIFME team recently published a September update - [click here](#)



And still not too late to enter the [GIVE IT UPtober 2016](#) campaign



Opposing MEGA - The Patients Voice

Firstly, a story about patient empowerment.

A UK group called MEGA (M.E./CFS Epidemiology and Genomics Alliance) has set up a petition for public support to help them obtain millions of pounds (estimated to be at least £9m) from research funding bodies for a prospective big scale -omics study of CFS/ME.

This group was formed by the Cmrc collaborative - which Invest in ME Research has [declined to join](#) and which includes some who were responsible for, or heavily supported the PACE Trial.



Invest in ME Research were asked our opinion of this MEGA project.

We responded when first asked and published an initial statement based on the very few details available at the time.

Since that time concerned and worried patients have set up a counter petition - **OMEGA - Opposing MEGA** - to counter claims being made by the MEGA group and in order to oppose the project. The charity was asked for its views on this.

Invest in ME Research read the OMEGA petition and we could only agree with the wording and sentiments of that petition

Having looked at the MEGA project in more detail and of those behind the project we are now even more concerned by this probable waste of public and private funding required - as well as the deleterious effect this project will have on the future for people with ME and their families.

At this time this project, and some of those involved in the project, dictate to us that it should not command support from patients - let alone funding from any public or private sources.

Read both of our statements here - [click here](#).

We support the sentiments in the OMEGA petition which states -

"No more wasting time, money, lives – not in our name."

"Things don't have to be the way they are -

we can change things"

- Dr Ian Gibson

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Invest in ME - Research

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Support ME Awareness - Invest in ME Research



One Event Can Change Everything

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

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.

Invest in ME (UK charity nr. 1114035)

www.investinme.org

email: info@investinme.org

ldifme.org

Small Charity
BIG Cause

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Invest in ME

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