



Invest in ME

NEWSLETTER



July 2013 Newsletter

Welcome to the July 2013 newsletter.
published 14/7/2013

INSIDE THIS ISSUE

| |
|--|
| CONFERENCE 2013 |
| IIMEC8 Pre-Conference Dinner |
| IIMEC8 Conference DVD |
| IIME BRMEC MEETING |
| A UK RITUXIMAB TRIAL |
| IIME FOUNDATION PROJECT |
| SEVERE ME |
| BIG FINISH PRODUCTIONS |
| BLUE RIBBON FOR ME |
| ALL THINGS BEAUTIFUL EVENT |
| IIME WIN DIRECT DEBIT COMPETITION |
| CARERS' GROUP |
| ME CARTOONS |

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

Invest in ME Research - Let's Do Research

IIMEC8 - Mainstreaming ME Research

IIMEC8
London
2013

The IIMEC8 conference and Biomedical Research into ME Collaborative meeting (BRMEC) were the most successful yet. **Mainstreaming ME Research** was the theme and title of the conference - Infection, Immunity and ME - reflecting our view that ME research is finally accepted as part of proper science and deserving of consideration for careers in research and for funding.

There was a great sense of optimism about the future of ME research. New researchers are learning about ME and becoming interested in this area of medicine. The data is pointing clearly to immune system dysfunction and the detective work is well underway to help solve at least some of the mysteries in this very complex illness.

Many of the body's systems are involved and there is a great deal of work for researchers from many different areas in different countries.

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. The feedback from the events confirm IIME's views -

- Mainstreaming was the right thing to do
- Informal meetings were important
- International collaboration was important
- A positive feeling existed that real progress being made with biomedical research

A conference report has been written by Dr Ros Vallings - [click here](#).

One can also read Mark Berry's report here - [click here](#).

[Conference Events](#)

IIMEC8 Pre-Conference Dinner

On the evening before the conference Invest in ME invited Open Medicine Foundation executive director, Linda Tannenbaum, to present "There Is A Plan".

Almost 90 people heard Linda discuss OMI's plans for **Mainstreaming ME Research**. The presentation in full is on our conference DVD.

[Read More](#)

IIMEC8 Conference DVD

The design and editing of the IIMEC8 conference DVD is just about completed and is about to be produced and distributed.

Unfortunately, we have had a request from Dr Øystein Fluge and Professor Olav Mella to hold off from including Dr Fluge's presentation in the DVD at this time.

This is because the Norwegian researchers have still not finalised their hypotheses for symptom maintenance in ME and do not feel comfortable with having this material distributed at this time. We are therefore bound to honour our agreement with Professor Mella and Dr Fluge.

However, the DVD still holds a great deal of education. It was the best conference yet.

We will retain the presentation from Dr Fluge and hope to come to an agreement on when it can be released at some point in the future.

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

IIME BRMEC MEETING

Prior to the conference IIME and AHMF had organised and hosted the Biomedical Research into ME Collaborative (BRMEC) meeting. This would actually be third such annual meeting organised in London around the conference events (we held a round-table "[Corridor Conference](#)" in 2011 and the two-day [Clinical Autoimmunity Working Group](#) (CAWG) meeting in 2012.

We brought together 40 biomedical researchers from nine different countries to discuss, educate, cooperate and form collaborations in the future - for the benefit of all people with ME and their families.

The meeting was a huge success with many complimentary comments being made by the researchers.

The researchers continued to network at the IIME pre-conference dinner in the evening. There were many threads and new initiatives created by this meeting and it justifies IIME's views that biomedical research into ME needs to be the focus of effort and funding if we are to create cures/treatments for this disease ([click here](#)).

IIME continue to follow up many of the opportunities created by this meeting.

[Read More](#)

A UK RITUXIMAB TRIAL

The charity is pleased to announce that following the IIMEC8 conference events we have started the planning for a UK rituximab trial.

In a very short time over £12000 has been raised for this trial reflecting confidence from our supporters and reflecting the urgent need for this trial.

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 welcome all support for this expensive, but necessary 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](#)

IIME FOUNDATION PROJECT

We are pleased to announce that the funds were raised for the foundation project for the IIME proposal for an examination and research facility in Norwich Research Park.

With great help from our IIME/LDIFME volunteer supporters the planned PhD studentship, which is looking at gut microbiota in ME patients, was advertised recently.

The closing date for applications was 24 June and the start date for the project is 1 October 2013. More information of the project can be [found here](#)

The project was also presented by Professor Simon Carding at the Invest in ME/Alison Hunter Memorial Foundation BRMEC meeting in London prior to the annual ME conference.

[Read More](#)

SEVERE ME

The situation of severely ill bedbound ME patients was also discussed by some of the presenters at the 2013 IiME conference. Some extemporaneous notes on severe ME from the conference, and after, are available here.

Doctors simply do not know what to do with these patients so there is an urgent need for education.

[Read More](#)

BIG FINISH PRODUCTIONS

Many Happy Returns, an audio play by Big Finish production company has already raised £4554.18 toward Invest in ME's biomedical research fund. This money was added to our UEA gut microbiota project fund in May. The play was released in November 2012 and is still available here.

[Newslet link](#)

BLUE RIBBON FOR ME

Another Invest in ME supporter, Jessica Jade, has a novel idea for fundraising anyone can join in.

"I have a blue ribbon. It is an awareness ribbon for this terrible debilitating condition. It's not much but I want it to help. I want it to raise money to help fund research into this neurological illness and to raise awareness along the way. So, I'm going to trade you. One blue awareness ribbon that I have, for something you have that's worth just a little bit more. Then, I'll trade that to someone else, who has something worth just a little bit more. And we can keep going, spreading the word and trading, until we can make a difference and maybe our final trade will help fund a cure. So get in contact with me if you want to help, if you want to trade or if you want to help spread the word. Everyone is welcome on this journey. The trade doesn't have to be an object, it can be a hand made craft or a service as well. (Like a haircut or something) The final item (i.e. when we get to an item that is really expensive and no one wants to trade for it) will be sold and the proceeds will be going to the charity Invest in ME."

Let's get trading!

[Read More](#)

ALL THINGS BEAUTIFUL EVENT

Valerie Moody organised a huge ME awareness and fundraising event - 'All Things beautiful' - in Co Donegal in Northern Ireland on 22 June 2013.

We thank Valerie and her family and friends for such great effort.



In 2011 Valerie published a book called 'Someone like ME' and Invest in ME received part of the proceeds that Valerie raised with this inspirational book.

Those funds went towards helping Invest in ME organise and host the first Clinical Autoimmunity Working Group (CAWG) meeting in London in collaboration with the Alison Hunter Memorial Fund.

Valerie is extremely inspiring as she is always positive despite her severe illness and looking for ways to make progress just as the young Alison Hunter. Valerie is an extraordinary example of courage and hope.

[Newslet link](#)

IIME WIN DIRECT DEBIT COMPETITION

Invest in ME want to thank all the voters who helped Invest in ME win the first prize of £2000 in April. Over 3600 votes were cast which is an enormous success for a 'Small charity with a Big cause'. The money was added to our biomedical research fund. Direct Debit published a press release which can be found at the link to the right.

This was another team effort with so many supporters, from many different countries, helping the charity to raise funds for and awareness of ME. The IiME/LDIFME initiatives have shown how positive and creative ME patients/carers/families are despite the great hardships they have to endure.

[Archive News items](#)

CARERS' GROUP

An IiME supporter has been thinking of introducing a Carer's Group for ME. As any carer knows it is not only the patient whose life is affected and with ME there are even less support network structures to help patients and carers than for other illnesses.

So Invest in ME are inviting people to write to us if you would be interested in forming this. There are many ideas which can be introduced into this with the objective being to improve the lives of carers and patients.

More information will be developed in the link to the right.

Contact us at info@investinme.org if you would be interested.

[Newslet link](#)

ME CARTOONS

We are pleased to publish a series of cartoons created by an ME patient who wants to remain anonymous.

These cartoons have been created over time due to severe illness and they reflect the person's own experiences of being diagnosed with ME.

These cartoons really show how an image and a few words can convey a message really well.

It's a Funny Old World - The Absurdity of Psychiatry.

Doctor, I have such horrible pain



[Read More](#)

[Return to Newsletter Home Page](#)

Invest in ME

UK Registered Charity Nr. 1114035

PO BOX 561, Eastleigh SO50 0GQ

Support ME Awareness - Invest in ME



Inquiries: All inquiries to Invest in ME - info@investinme.org

To unsubscribe from this newsletter send an email to info@investinme.org
and entitle the email **unsubscribe**.

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

[Go to Newsletter Home Page](#)