Invest in ME
NEWSLETTER
September 2014 Volume 9 Issue 2

Charity Nr: 1114035

# Welcome to Our September Newsletter

*From IiME*

Greetings.

This month's pdf version is a round-up of both published September e-newsletters and reflects our intention to produce a fuller magazine to accompany the newsletter going forward. In this we have been working with our Let's Do It For ME colleagues and taking on board their advice.
In future this will transform into a monthly document which describes the work the charity and our supporters are doing together.

In this newsletter we have news of the biomedical research projects which the charity has initiated and funded.

We also have details of our conference events of 2015.
There are real grounds for optimism now that the charity and its supporters have been able to build a foundation for a long term strategy of biomedical research into ME. Our foundation project has begun at University of East Anglia and the Institute of Food Research to analyse gut microbiota in ME patients.
At the 2012 conference we stated that we were working on an attempt to set up a rituximab clinical trial. Following our Biomedical Research into ME Colloquium in London last year we have made rapid progress by partnering UCL in setting up the planned UK rituximab clinical trial.

In our ninth year as an organisation we can say each year has been a stepping stone in breaking the mould and bringing ME into mainstream in research and media.
Funding is scarce and the efforts of our supporters to make up what has been lacking from government agencies and research funding organisations have been awe-inspiring.

Progress is a fine word but change is its motivator – and people with ME and this charity have made that happen.

Millions of patients are suffering around the world and the ratio of money being spent on this disease to the economic and

## INSIDE THIS ISSUE

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societal losses it causes is at odds with any scientific, economic or moral viewpoint. It is organisations such as the MRC and the NIH in the USA that need to perform much of the soul-searching regarding this. It is the attitudes of people in these organisations that have been a perennial problem.

We actually agree with the remarks attributed to Professor Stephen Holgate of the MRC last year when he stated that we are bathing in a sea of ignorance regarding ME. Yet it is rather disingenuous 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.

Organisations such as the MRC and the NIH have been filling the ME research bath for all these years and patients have been drowning from the effects of ignorance about ME.

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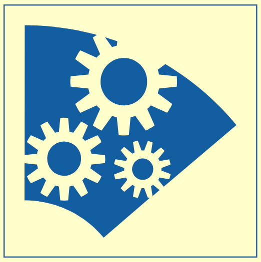
The failed and flawed PACE Trial, for all the spin and waste of scarce funding, did prove one point emphatically - that the behavioural view of ME cannot deliver and should not continue to command more funding.

A strategy of biomedical research into ME with a research group being formed consisting of biomedical researchers, using resources and facilities across continents - hooked up to share research and data and crowd fund new research. Our vision of the future.



Future research into ME can be based on collaboration - but not collaboration at any cost. It would seem quite meaningless to base the strategy on those failed policies and directions of the past - which have served patients so poorly and caused such suffering. These wheels within wheels need to be broken up as they serve only those who seek no change.

Such is the meaning behind our Invest in ME Biomedical Research into ME Colloquiums which we have organised for four years and which precede our annual research conference.

These aim to interest other researchers to the field of biomedical research into ME, assist those who are undertaking research or planning research into ME, and look for future collaborative projects and funding which could be generated by new ideas.

This Colloquium, now in its fifth year and which this year had attracted almost fifty delegates from ten countries, is (in 2015) two full days of researchers meeting together and is designed to encourage collaboration and sharing of experience and to bring in new ideas and knowledge from outside the field of ME.

A small charity with a BIG cause can achieve this.

The government, their organisations and the media have a lot of catching up to do.

Listen to the patients is still a maxim to which politicians and the media should pay heed.

## IiME ADVISORY BOARD

Invest in ME
Research
Advisory Board
www.investinme.org

As mentioned in last month's newsletter the charity has formed an advisory board of top researchers to help with planning the strategy for future biomedical research and also for other events.

The first advisory board meeting was held in late August 2014 in London.
Together we are working
on establishing the correct science to be involved in ME research and on determining ways of using objective methods for identification of cohorts of patients who can be put forward for research.
A number of key areas and possible projects have already been identified.

We believe our approach to initiating biomedical research into ME is paying off and feel that the key elements of a correct and productive strategy of research into ME are being, or have been created.

***More details***

## IIMEC9 Conference DVD September Offer

The IIMEC9 conference DVD is available and for September for any order for the DVD we will include a printed copy of the BRMEC4/IIMEC9 Report document (see article below) and an IiME wristband.

The DVD can be ordered via this link - click here.

Also in September we are offering your very own Professor Ldifme bear for £10 - which includes postage and packaging.

A great present just in time for Christmas.

Professor Ldifme is now gracing research labs around the world and raises the LDIFME flag.

***Read More***

Invest in ME Research - Let's Do Research

## BRMEC5 COLLOQUIUM / IIMEC10 CONFERENCE - 2015

Invest in ME announced its plans for IIMEC10 - our tenth International ME Conference 2015 - for Friday 29th May 2015 in London.

We also announced our fifth research Colloquium preceding the conference for Thursday 28th May 2015.

The trustees have decided, after consultation with our Advisory Board, to extend the research Colloquium to two days.
The event will now be Wednesday **27th May to Thursday 28th May**.

This was the format that was employed in our 2012 Colloquium - the Clinical Autoimmunity Working Group meeting [*Clinical Autoimmunity Working Group (CAWG)* [ meeting in 2012.
Both events will be in London and we already now have interest from eight countries in participation and we continue to build international collaborations to discuss and resolve this disease.

It is difficult to believe that the charity is looking at its tenth biomedical research conference. The first conference in 2006 was experimental, organised shortly after Invest in ME became a charity.
Our 2007 conference was also an experiment over two days which looked at separate professionals and patients days.
But it was from after the 2007 conference that the charity's focus became more organised as we looked at the future and what was required. It was from that point that our intent to coordinate biomedical research across countries began to be formed.

The conferences and, later, the Colloquiums have been generating new

research and opportunities for years. Our conferences have been facilitating discussions and sharing of information between patients, researchers and clinicians for almost 10 years.
The charity has now put in place the key building blocks to progress ME research with high-quality biomedical research in world class organisations being performed by some of the best researchers.

The IIMEC10 celebrations will include a pre-conference dinner following the research colloquium and the full day conference itself - for the tenth year in succession taking place in the heart of Westminster.

Ten years of of researchers, clinicians, healthcare professionals, patient groups, patients and the media being able to discuss, network and debate.
The conferences have made patients into partners in research – something which is been ongoing and has been happening regularly since the early IiME conferences.

***More details***

## IiME BRMEC4 REPORT DOCUMENT

We mentioned in last month's newsletter that IiME have produced a report for GPs and healthcare staff showing the extent of current biomedical research into ME which is being performed.

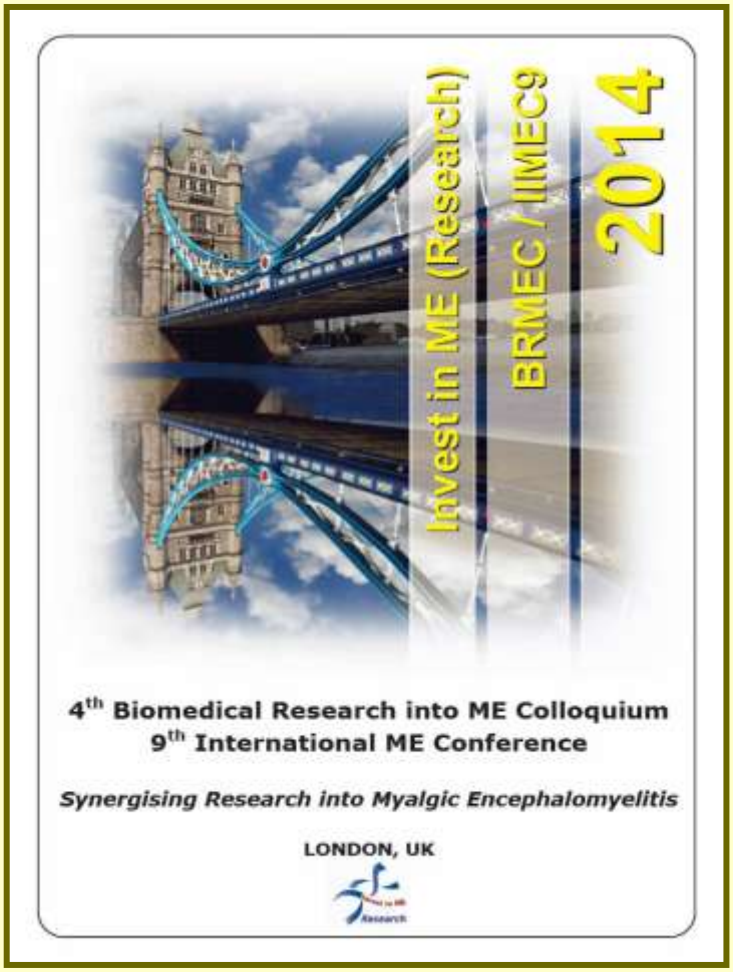
The charity has printed copies available and we are happy to send them to any healthcare professional who may find it useful or to ME support groups.

Please contact the charity to arrange this - contact us.

In the meantime we are now publishing the copyrighted document on our web site for people to refer to.

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.

***Read More***



Invest in ME (Research)
BRMEC / IIMEC9
2014

**4th Biomedical Research into ME Colloquium**
**9th International ME Conference**

***Synergising Research into Myalgic Encephalomyelitis***

**LONDON, UK**

# Invest in ME/UCL Rituximab Trial - Project Update

At or advisory board meeting Dr Jo Cambridge gave a presentation on the status of the UK Rituximab Trial project.

Dr Cambridge has also produced for IiME an update which we are pleased to publish on our web site.
We would like to thank everyone for the continued support as we build up a contingency fund for the trial.

The campaign to raise funds has been a truly international event and has involved supporters from all over the world [click here].

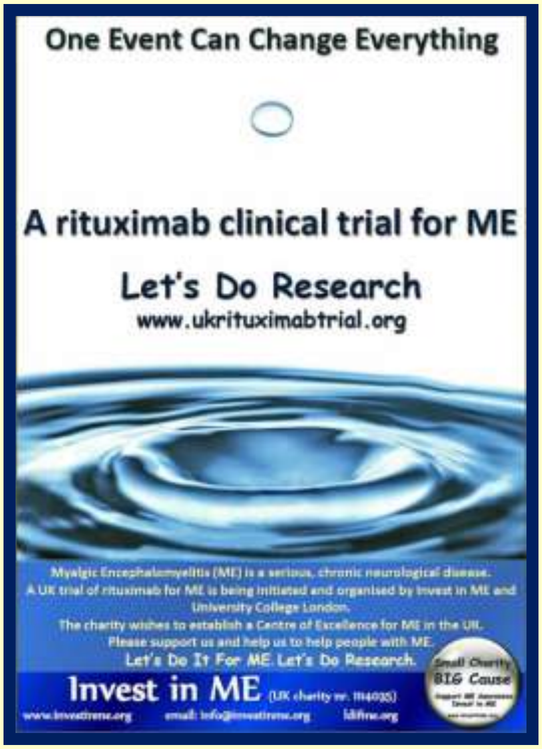
Having reached our initial target for the IiME/UCL Rituximab trial, and with the preliminary B-cell study in progress, Dr Jo Cambridge produced a project status update [click here].

The charity has discussed with our Advisory Board on future directions and earlier in the month we announced our intention to fund a PhD studentship.

We have asked our supporters again to help us enable this crucial research.

The charity has formed a good working relationship and initiated state-of-the-art research with world class researchers who are the most experienced in this area in the world.

As part of objectives to form a solid base of biomedical research we are committed to making this additional research possible.
It also reinforces our plans for a Centre of Excellence proposal.



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.

A further update on this has now been produced for Invest in ME by Dr Cambridge and describes the intentions with this latest planned research.

This is available via this link - click here.

***Rituximab Web Site***

# UK Gut Microbiota Research Update

Our Biomedical Research Foundation Project at IFR/UEA, the UK Gut Microbiota study, is now ending its first year.
The foundation project was devised in 2010, long before it became fashionable as an area of research for ME, and was galvanised by the launch of the Let's Do it for ME (LDIFME) campaign in 2011 to help the charity with fundraising. It took us and our supporters three years to reach the first funding target of £100 000.
We quoted from Dr Lipkin (Director Centre for Infection and Immunity at Columbia University) a year ago when the project began ["I think the gut microbiome is going to be where the action is (in ME)" - Lipkin Presentation CDC Conference Call 10/9/2013 ]
We are pleased to see this research being performed by a world class research establishment at the Institute of Food Research/UEA in Norwich Research Park.

We are currently fundraising toward our Biomedical Research Fund in order for us to make progress on new ideas that have been identified by our advisory board.
All research projects are peer-reviewed prior to any final funding decision.
Our research funding guidelines can be found here.

After getting the first project up and running it has been easier for the charity to plan for follow on projects and the forming of our Advisory Board has been very helpful.

IiME have now provisionally agreed with UEA for the creation of two new PhD studentships for this research in the research park which will cement the foundations of biomedical research into ME for the next three years.
A project description is being formulated to complement our foundation project.
The strengthening of the research base and the continuation of the biomedical research into ME work that has been started has been a priority for IiME. Our objective since 2007 to establish high-quality international collaboration to resolve this disease – is also on the way to being realised.

We have been working with UEA to attract more medical students (MRes) to join in with the Invest in ME (Research) funded projects and we are delighted to announce that we are also agreeing with IFR/UEA the funding of new intercalating medical students who would spend time at Oxford university in UK and Cornell University in New York, USA in ME related research projects.
This would mean that the charity is funding three medical students to perform biomedical research into ME - thus allowing real knowledge of the disease to be spread around medical schools.

Three PhD studentships and three MRes intercalations at the UEA – in addition to the plans at UCL!
All of our plans are building on our original proposal for a UK Centre of Excellence for ME - see here.

The research team has provided an update on the current status of his work - click here.

# FUND/AWARENESS RAISING

IiME supporters continue to inspire with their fund-raising and awareness projects.

## Arctic Marathon

We have previously written about Mike Shepherd's plan to run the North Pole Marathon in April 2015 to raise funds for Invest in ME [see February newsletter].
This will be quite a challenge for Mike and involves a gruelling training schedule - and supportive family. You can support him here http://www.justgiving.com/Mike-Shepherd or just raise awareness via sharing the link.

## European Multi-Marathons

Mike Harley (who led the amazing 92 in 92 event which visited all 92 football league clubs) is also planning an extreme marathon - extreme in terms of numbers - click here - by attempting to conquer Europe by running a full marathon in every country in the EU (currently 28 in total). In this we will ask our European ME Alliance colleagues for support.

## Deborah's Born Survivor Marathon page

"*Thanks to the magic of Facebook I have been back in touch with a childhood friend who I have not spoken to in over 25yrs (who knew I was that old!!) Sadly she suffers with ME and even though we made contact in April this year but due to the debilitating illness she has we are yet to meet up in person, and she only lives 7 miles away!*
*I am lucky enough to be able to attempt 120 obstacles over 42km so I can raise some money to help fund research and treatment then maybe one day she will be well enough to join me.*"

https://www.justgiving.com/Deborah-Jane-Armstrong/

## Just Giving

We thank all the great supporters of IiME who have set up Just Giving pages to raise funds for our work. Please support these events as much as you can. Even if you cannot afford to donate you can help by highlighting these great efforts/events.
http://www.justgiving.com/investinm-e

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### *DID YOU KNOW*

***The UK Rituximab web site has a Frequently Asked Questions (FAQs) where common questions about the project are answered.***

***Click here***

***Similarly with the UK Gut Microbiota Project we have a FAQ link – click here***

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# Let's Do It For ME NEWS

## Fundraising news from the Let's Do it for ME blog

### From ME to You, With Love - new website launched! By Louise Harding

"Since the book 'From ME to You, With Love' launched in May, it has done incredibly well. Almost 250 copies have been sold, and the amount of money donated to Invest in ME is now around £300 so far. The book is available either in paperback or on Kindle."

### I swam the length of Coniston, all 5.25 miles of it!   by Sarah Loveland

"On Saturday the 6th September Sarah Loveland swam the length of Coniston Water, all 5.25 miles of it, for Invest in M.E.
Sarah is a so-called 'wellie' but she has friends with M.E. Over the past year, her eyes were opened to what a debilitating illness it is as she read stories of individual challenges to raise funds, such as one person walking to the garden gate.
This inspired Sarah and she set her swimming challenge, Sarah decided that if courageous people with M.E could challenge themselves to raise funds then she could swim the length of the lake for them.  By trade I'm a photographer at Sarah Loveland Photography and this was only her second year of open water swimming.

Last year when I started I wasn't very good and I could only do half a length of the pool front crawl. I built that up to complete several one mile events.
At the start of this year 5.25 miles seemed impossible but I was determined. Stubborn, determined and perhaps a little bit crazy!"

*Making a Difference*

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## *LDIFME*

***Let's Do It For ME recently passed their third anniversary***

***They have not only worked with us to achieve unique crowd funding opportunities for biomedical research into ME – they also achieved this via positive means, focusing on what we can do not what we can't.***

***Let's Do It is now a phrase synonymous with getting results rather than just talking about it.***

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## Hurst Family Fundraising for ME! By Jane Hurst

"I have suffered with this horrible illness – ME – for over 16 years. I also have Dysautonomia, and was recently diagnosed with Elhers Danlos Syndrome.
I have too many symptoms to list, most of them invisible, but the symptoms that cause me most distress are the severe chronic pain and the disabling and very uncomfortable circulatory/cardio vascular problems.

I spent the first 2-3 years of the illness completely bed-ridden & all of the past 16 years housebound (mostly bed-ridden) but due to the pain I experience now I am unable to lie down and sitting down is too painful a lot of the time, so life is extremely difficult, having to stand hunched over my bed for hours each day even though this causes me to feel very faint & exhausted.
I try to be positive but if I'm honest most days are nothing short of an endurance. This is also the case for many of my fellow Severe ME/EDS sufferers."

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>
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## Christmas Cards 2014

The 2014 Christmas card competition has closed and Julia Cottam and the team have again produced some fantastic results which will once again raise the profile of ME as well as potentially help raise vitals funds for biomedical research into ME.

We are just deciding the format and sizes of the cards but we have already decided the price and these can be seen on our Christmas 2014 page.

We also still have some Christmas cards over from last year which are available - including the Independent Newspaper's Indybest Christmas card winner ***Candle House*** by Julie-Ann Gylaitis.

# Old (New) and New Research

Dr Jonathan Kerr was a regular presenter at our early conferences but moved on from ME research. A paper from Dr Kerr's research has, however, just been published.
*J Clin Pathol* doi:10.1136/jclinpath-2014-202597 - click here

Use of single-nucleotide polymorphisms (SNPs) to distinguish gene expression subtypes of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) - Nana Shimosak Jonathan R Kerr

**Abstract - Aims**
We have reported gene expression changes in patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and the fact that such gene expression data can be used to identify subtypes of CFS/ME with distinct clinical phenotypes. Due to the difficulties in using a comparative gene expression method as an aid to CFS/ME disease and subtype-specific diagnosis, we have attempted to develop such a method based on single-nucleotide polymorphism (SNP) analysis.

**Abstract - Conclusions**
This study provides evidence that human SNPs located within CFS/ME associated genes are associated with particular genomic subtypes of CFS/ME. Further work is required to develop this into a clinically useful subtype-specific diagnostic test.

Meanwhile Professor Sonya Marshall-Gradisnik's research, presented at our IIMEC9 conference (and the embargo of which caused a slight delay in our conference DVD delivery), has now been published **[1].**

**Abstract - Background**
MicroRNAs (miRNAs) are known to regulate many biological processes and their dysregulation has been associated with a variety of diseases including Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).
The recent discovery of stable and reproducible miRNA in plasma has raised the possibility that circulating miRNAs may serve as novel diagnostic markers.
The objective of this study was to determine the role of plasma miRNA in CFS/ME.

**Abstract - Conclusion**
Our study is the first to identify circulating miRNAs from CFS/ME patients and also to confirm three differentially expressed circulating miRNAs in CFS/ME patients, providing a basis for further study to find useful CFS/ME biomarkers.

1. Brenu EW, Ashton KJ, Batovska J, Staines DR, Marshall-Gradisnik SM (2014)
High-Throughput Sequencing of Plasma MicroRNA in
Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

PLoS ONE 9(9): e102783. doi:10.1371/journal.pone.0102783
[click here]

## European ME Alliance

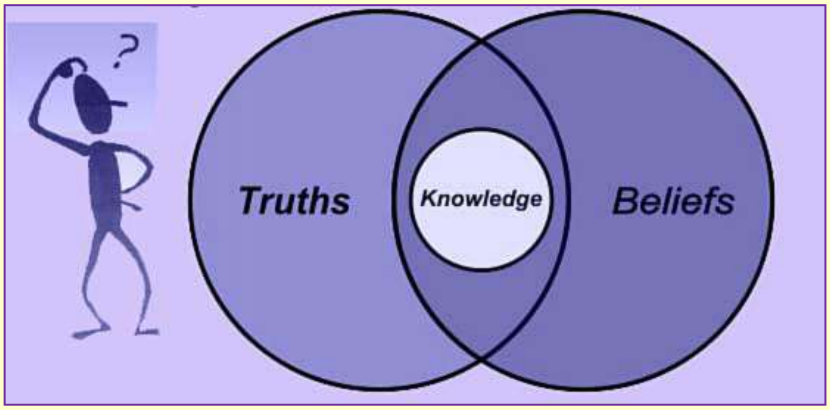
Our Swedish colleagues at RME are hosting a seminar in the autumn in Stockholm
The subject is ME and Children and is primarily aimed at professionals in the health care and schools.

The seminar will be mainly in English.
Speaking at the seminar will be –

Dr. Peter C. Rowe, Johns Hopkins Children's Center, United States Pediatric ME / CFS
Dr. Nigel Speight, The University Hospital of North Durham, UK
Dr. Amolak S Bansal, Dept. of Immunology, St. Helier Hospital, Carshalton, Surrey, UK
Nathalie Gillberg and Camilla Gillberg - patient and parent

More details click here.

## Margaret Williams



We have reason to hope that permanent change is on the way thanks to the efforts of IiME supporters. The new research we have been able to initiate independently has real possibilities to change the way ME is perceived by the medical profession and the general public and we know this is already influencing what is happening elsewhere.

During all the years before IiME could initiate this research we, along with other individuals and organisations, had to campaign and lobby to try to break the stalemate which establishment organisations had quite happily allowed to continue.

One of the most notable advocates has been Margaret Williams. Her factual commentaries on what has been happening with ME have been indispensible. Margaret Williams' articles have empowered patients to challenge dogma and poor science and overcome the inaccuracies and policy-based evidence making which has been allowed to exist regarding ME.

We are no great seekers of awards but there are few with better credentials for deserving recognition than MW.

*(An example of MW's articles - THE IMMUNOLOGICAL BASIS OF ME/CFS: what is already known? A compilation of documented immune system abnormalities in ME/CFS from 1983-2011 - is in the Journal of IiME Volume 6 Issue 1 2012 –*click here )

# INVEST in ME (RESEARCH)

Invest in ME (Research) is a charity made up of volunteers with no paid employees and all the work the charity and its supporters do is entirely without payment.

See About us - http://bit.ly/19bC17p

Each year the charity organises and hosts an international biomedical research conference in London - attracting researchers, healthcare professionals, clinicians, patient groups and patients from many countries.
We have supplemented these in recent years with a Biomedical Research into ME Colloquium – including hosting the first Clinical Autoimmunity Working Group for ME in 2012. The 2014 Colloquium 4 was held in London with almost 50 researchers from 9 countries attending, prior to the IIMEC9 International ME Conference 2014 - http://bit.ly/ZsmSEj

The charity is a founder member of the European ME Alliance and has collaborated with international organisations.
Our aim is to build sustainable and developing collaborations with translational biomedical research at
the heart of all research into ME.

The Let's Do It For ME campaign aims to help IiME raise funds for biomedical research into ME – see http://ldifme.org/

The Let's Do It For ME Story – see http://bit.ly/15XheiL

## USEFUL LINKS

| | |
|---|---|
| IiME CONFERENCE DVDs - | http://bit.ly/10YB6n3 |
| Biomedical Research Fund - | http://bit.ly/10Ls9vJ |
| IiME on Facebook - | http://on.fb.me/135oHdh |
| IiME on Twitter - | http://bit.ly/14vq0I3 |
| Help us - | http://bit.ly/18x4WDz |

**Newsletter Home Page**

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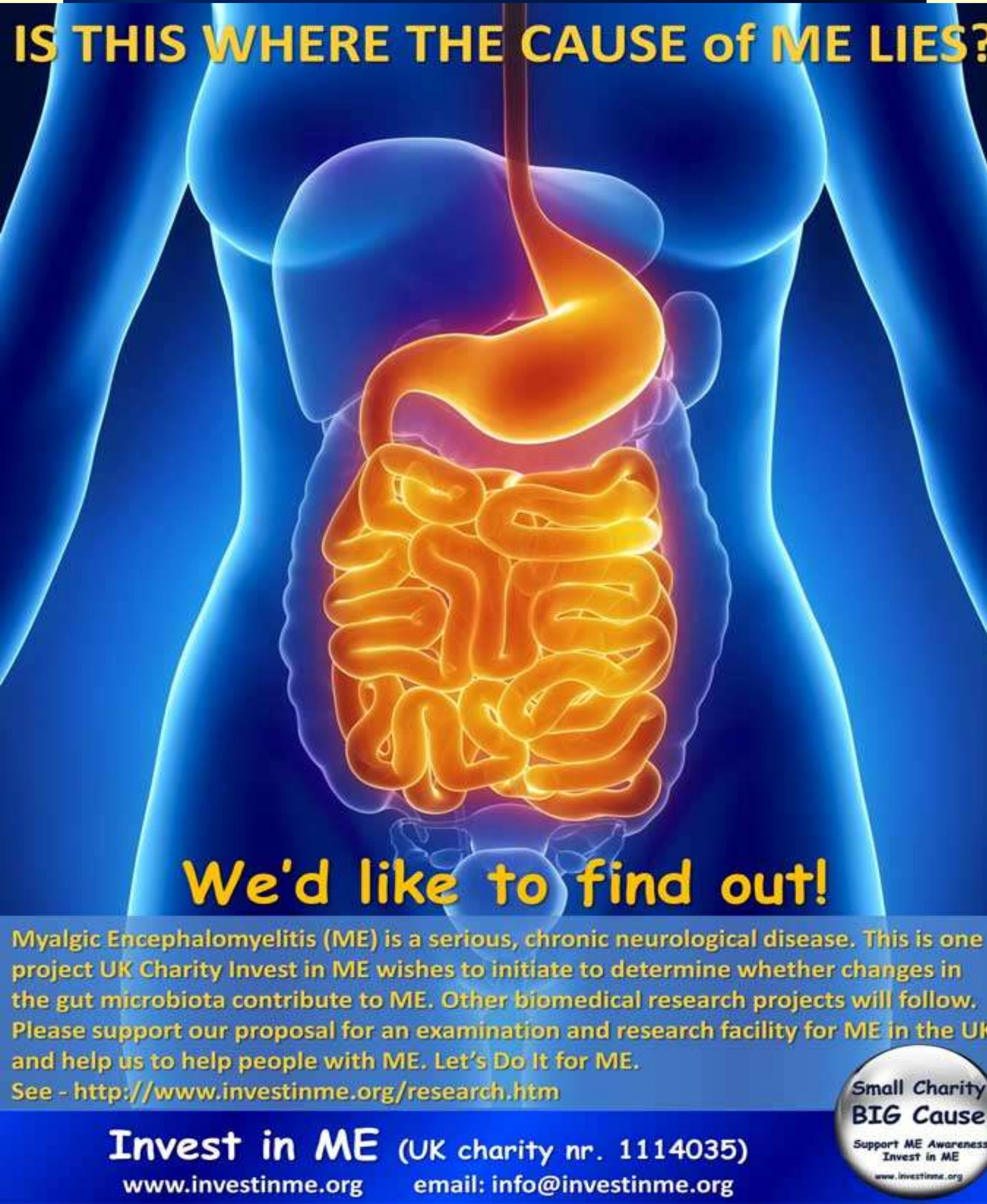
***Support ME Awareness - Invest in ME Research***



Myalgic Encephalomyelitis (ME) is a serious, chronic neurological disease. This is one project UK Charity Invest in ME wishes to initiate to determine whether changes in the gut microbiota contribute to ME. Other biomedical research projects will follow. Please support our proposal for an examination and research facility for ME in the U and help us to help people with ME. Let's Do It for ME.
See - http://www.investinme.org/research.htm

**Invest in ME** (UK charity nr. 1114035)
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