Invest in ME
NEWSLETTER

Invest in ME
Research

INSIDE THIS ISSUE

> *"the only people who can be said to be afraid of exercise with regard to ME are those who are afraid to exercise their minds."*

Welcome to Our January Newsletter

Greetings from IiME. Welcome to the first short newsletter of 2015.

It has been an extremely busy time over the last few months for the charity with a great many activities taking place behind the scenes.

Our intention last September was to continue to publish a monthly newsletter with a fuller magazine version in pdf format.
But there have been a number of reasons why this plan was delayed – mostly to do with the amount of effort required to make change happen but also dealing with the consequences of ignorance about ME. The charity still deals with requests to help patients and families including, incomprehensibly, efforts to avoid patients being sectioned or attempting to help attain their release once sectioned. This still happens.

Apart from conference event preparations, advisory board meetings, looking for new research opportunities, constructing new websites and looking at new campaigns we have also contributed to a successful Christmas card competition organised by Julia Cottam and the team, which culminated in the distribution of thousands of Christmas cards to ten different countries. Thanks to everyone taking part in the competition and to those who purchased the cards.

Whilst the charity prefers to look ahead to what we Can Do it is, nevertheless, a fact of an ME patient's life that they have to deal with the prejudice which proliferates with regard to ME – mostly created and aided by establishment organisations but fed also by ignorance about the disease and misinformation which is allowed to accumulate.

The PACE trial is a compass point for this misinformation and in recent weeks the myopic media again lost its direction and followed the path to nowhere by publishing the latest charade from the PACE trial – this time claiming that ME patients are afraid of exercising.

The PACE trial is the epitaph to a generation of failed policies of those supporting the psychosocial view of ME – a view now buried in ignominy.
The psychosocial approach to ME has failed because it is founded on flawed theories and vested interests. Indeed the only people who can be said to be afraid of exercise with regard to ME are those who are

afraid to exercise their minds and listen to what patients are telling them.

In this newsletter we also have news of our response to the BBC's coverage of the PACE trial's latest rehash.

The charity has also made a submission to the US National Institutes of Health (NIH) regarding their Pathways to Prevention Workshop Draft document - a document which seemed to look forward in many ways by recognising what needs to be done in some areas, whilst at the same time attempting to cling to the past by including other areas that have caused so much harm to ME patients.

That is a strategy which has no chance of succeeding and we have stated so.

Dena's story is one which ought to be read by those in the media who decide on the stories and headlines in health news.

Finding the cause(s) of ME and possible treatments may not be easy. But it has been made even more complicated by the actions, decisions and policies of those who have had responsibility for research funding and those who have controlled the media disinformation about ME.

Organising the conference events is no small task and has been occupying the team since September last year.

For IiME the conference events will consist of 4 or 5 events following one after another.

The 5th Invest in ME Biomedical Research into ME Colloquium is set up to enable and facilitate the collaboration and sharing of experience between biomedical researchers from inside and outside the ME research area.

This approach has provided a number of initiatives and projects already and proves that biomedical research can be arranged without the impediment of non-essential paradigms. With a number of networking and discussion sessions being arranged then we hope that more progress will be made.

Progress from these events will not necessarily directly benefit IiME in terms of enabling us to do more. But it will, we firmly believe, benefit ME patients in Europe and elsewhere.

Bridging the research colloquium and the public conference will be a pre-conference dinner – another opportunity for patients, researchers and clinicians to interact.

> ***The PACE trial is the epitaph to the failed policies of those purporting to believe in the psychosocial view of ME – a view now buried in ignominy***

Following the IIMEC10 conference work does not stop as IiME will host and chair the European ME Alliance AGM. EMEA, now thirteen countries, will also have news of a new member which will strengthen the Alliance.

IIMEC10 will be the culmination of ten years of conferences and also begin our tenth year as a charity. It is an appropriate time to look at how far things have come in ten years. The answer is not far enough. All through this time in the UK we have been weighed down by apathy, indifference and attitudes which seek to maintain the status quo – or at least not move things too quickly.

But the charity's supporters can be justifiably proud of making things happen, of changing the landscape in the UK, and building the foundations of a future of valid research.

It is without doubt that our supporters have forced others to act.

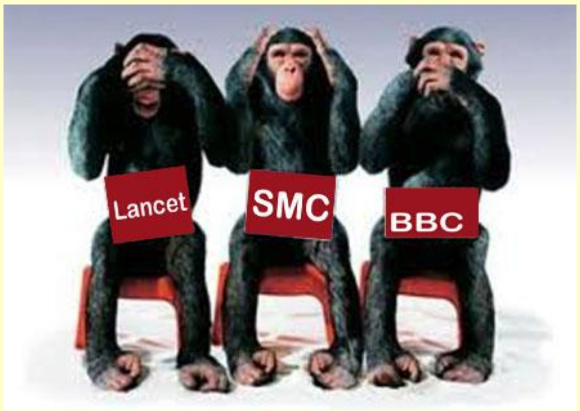
And we'll continue to make change happen and seek and facilitate change elsewhere – hence our view that international collaboration in translational biomedical research is the way forward and the rationale behind our research colloquiums.

For those who have had reason to despair after the recent sound bite healthcare headlines regarding PACE then we would say that things will change.

The speed of change will depend on how much the agents of change can harness their potential to make progress.

Best Wishes - All at IiME

Addressing the Fear of Learning About ME



In a week where the media has again distinguished itself by its failure (or unwillingness) to perform adequate background research about ME then patients have again distinguished themselves by their articulate obliteration of the falsehood of the PACE trial and all of its subsequent fatuous spin-offs.

The fantasy storyline painted by the Science Media Centre (SMC) has been quite overwhelmingly countered with facts and observations by the ME community based on logic, science and common sense and once again dismantles the establishment spin about this illness.

The orchestrated efforts to publicise the latest product from the already discredited PACE trial claimed that ME patients are fearful of exercise [**1**].

As always the establishment press goes to the establishment organisations and individuals for comment - thus distorting even further the perception of ME.

Garbage in garbage out!

Invest in ME have, in the past, responded strongly and honestly regarding the PACE trial but yet again, on this occasion, the charity was not given any forward warning of this publication in order to be able to prepare, nor asked for comment.
Fewer and fewer in the scientific community are going to take this latest paper seriously but it is extremely irresponsible of the broadsheet science journalists not to ask any investigative questions or explore the subject matter further before coming up with puerile headlines such as “Tackling fears about exercise is important for ME treatment".

Some good responses can be found in the BMJ comments section
http://www.bmj.com/content/350/bmj.h227/rapid-responses

And the damage is not just to science.
Once again sick ME patients have to experience harmful consequences of this gross misinformation.

The devastating effects such headlines can have on the health of sick and vulnerable ME patients is ignored by all those who have contributed to allowing this false research to dominate funding and news desks. The people behind these headlines, and those maintaining the current misinformation about ME seem to care nothing of the harmful effects on patients.

“Garbage in garbage out”

Also of note is what we perceive to be the hypocrisy behind some of the denunciations of this research from those who actively support the PACE trial and/or sit on the same Medical Research Council (MRC) CFS Collaborative Executive Board as the Principal Investigator of the PACE trial.
Some founding member organisations of that collaborative may be making public statements trying to distance themselves from PACE but it rings somewhat hollow to us. They were quite happy to be part of writing a charter for the CMRC that states–

"*the definition of harassment is that stated in the Protection from Harassment Act 1997. It was also highlighted that while the conduct must be unwanted by the recipient, it does not necessarily have to be that the harasser has a motive or an intention to harass. Therefore it may still be deemed harassment even if the harasser does not know there is harm caused by their actions*." (source: minutes, board meeting 17 Dec 2014)

We wonder why this latest onslaught from the media is not considered harassment of ME patients. It does seem incredible that the SMC is actually represented on the CMRC executive board and attends all meetings. The CMRC was supposedly formed to encourage more research into CFS/ME yet here they are leading the publicity of this latest

attempt to represent the PACE trial as credible science.
Although these actions seem totally disingenuous and incomprehensible to us what it clearly does demonstrate is what little effect appeasement toward the psychosocial lobby has on the fortunes of ME patients.

But the Science Media Centre perhaps need to be congratulated on one thing though.
In the April 2013 SMC briefing, at the launch of the MRC CFS collaborative, the prevalence number publicised was a mythical **600,000** patients in the UK [**2**]. This was even repeated by a MRC representative speaking in an Australian conference in 2014.
In the recent "fear of exercise" media hype the SMC reverted to the most often quoted prevalence of **250,000** figure [**3**].

Impressive!
A wonderful recovery of so many patients in such a short time! …………………. or perhaps just indicating a complete lack of any substance or real strategy underpinning the MRC strategy toward ME.
Graham McPhee clearly illustrated the distorted MRC policy over the years in his brilliant You Tube video **Science Friction** - depicting the bias in spending on ME research – click here.

Margaret Williams has neatly summed up the total psychosocial concept as a “null field” – click here
We could not agree more!

References:

1. Rehabilitative therapies for chronic fatigue syndrome: a secondary mediation analysis of the PACE trial Chalder T. *Lancet Psychiatry.* 2015;doi:10.1016/S2215-0366(14)00069-8
2. http://bit.ly/1BfBaeY
3. http://bit.ly/1JPvTj0

> **“Apart from anything else I am saddened to see poor data of this sort being used in a way that will perpetuate the lack of trust between patients and their carers. The patients are very aware of the weaknesses of the study and I am surprised that those designing the study are not equally aware."**
>
> - *Jonathan CW Edwards, Professor of Medicine, Emeritus, University College London*
>
> *BMJ Rapid Responses*

The BBC belatedly joined in the spin with this article – click here - carrying the misleading title "Exercise can help with ME, scientists say"
The BBC have an even greater responsibility to be balanced and avoid biased and misinformed journalism - it has a charter which explicitly forces it to do so. This they did not do and therefore received a complaint from Invest in ME about their reporting standards and this particular article.

The Invest in ME complaint is documented on our web site – see here

We will report the BBC's response - if and when it comes.

A Patient View

An appropriate time perhaps to mention our article from last year which was submitted by Dena Graham –

THE TRUE BATTLE WITH CHRONIC FATIGUE SYNDROME

which Dena wrote for the charity to show the patients' side of the story - something that the MRC, SMC and others seem incapable of understanding.

> "Except, for many CFS sufferers, the true battle begins when it comes to other people’s perceptions of it. To be so ill, yet dismissed by so many, is a harsh blow. Worse when it comes from people who you think ought to know you better."

Dena's story can be seen here

NIH National Institutes of Health
Office of Disease Prevention

IiME SUBMISSION TO NATIONAL INSTITUTES OF HEALTH

PATHWAYS TO PREVENTION WORKSHOP

Invest in ME have submitted a response to the USA National Institutes of Health P2P draft report. In the document Invest in ME have made the following points –

- we recommend the need to divorce the failed psychosocial paradigm from the biomedical research for ME and the avoidance of mixing under one umbrella a set of disparate conditions
- we recommend that the NIH should **NOT** to follow the UK example of NICE or the MRC
- We recognise that the draft document makes many valid and sensible points and observations but also some very odd statements that create concern that another agenda is being served - with “inexplicable references to bringing in components which have contributed to the abysmal situation in which ME/CFS patients find themselves”.
- We believe future research into ME/CFS needs a strategic approach - but is destined to fail completely by attempting to establish the way forward on foundations which include so much of what has been wrong in the past.
- We believe we need not just funding, but correctly defined cohorts, standardisation on diagnostic criteria and a collaborative of researchers who will not blur science with orchestrated politics.
- We suggest that the NIH finally and totally abandon all links to the psychosocial model with regard to ME/CFS research funding
- We suggest that instead of relying on alternative funding streams elsewhere that the NIH take responsibility themselves for ME/CFS.
- We recommend that the NIH invest $50 million per year for the next five years in biomedical research into ME/CFS.
- We suggest trying this for a 5 year period with a yearly review of progress and a final conference/workshop/committee to be convened to examine progress.
- We recommend that the NIH provide correct and current education into the disease which will, in turn, raise appropriate awareness.
- We suggest these recommendations will lead to scores of biomedical research projects, international collaboration, new ideas and new skills entering ME research.
  They will facilitate the harnessing of the full potential of academic and research institutes and galvanise science - eventually forming pockets of research expertise which will create the centres of excellence for the future.

Above all we emphasised to all the urgency of the need for action and change.
The full submission by Invest in ME can be followed from this page - click here.

We also invited the NIH to be represented at our fifth Biomedical Research into ME Colloquium in London on 27-28th May 2015 in order to begin the journey of change and join our international collaborative effort to resolve this illness.

IIMEC10 2015 - Ten Years of Biomedical Research

The charity has added the first of our confirmed conference speakers to the web site for the IIMEC10 conference on 29th May in London.

Our tenth conference begins the tenth year of Invest in ME becoming a charity.

If we had had the resources available to use on celebrations then we would have reminisced on ten years of effort to raise awareness of ME and initiate biomedical research into the illness. However, all funds go to making things happen. So we will suffice by attempting to put on the best conference possible and to arrange our fifth Biomedical Research into ME Colloquium on the days before in order to create opportunities for progress, via change.

We welcome back old friends from Norway – Dr Oystein Fluge and Professor Olav Mella – who will be presenting news of their formidable ME/CFS research efforts. They are not just performing a multicentre phase III rituximab trial but they have many sub studies as well. This is a unique opportunity for healthcare professionals and researchers to learn about innovative ME/CFS research that opens up a whole new era.

The IiME rituximab research team are working with the Norwegians and Dr Jo Cambridge from our UK rituximab research team will be giving a status update also.

We also welcome back Associate Professor Mady Hornig from Columbia University in New York and Dr Amolak Bansal from Surrey, UK.

We hope to add a pre-conference dinner to allow more discussions amongst researchers and patient groups.

More information will be carried in our news page - click here - and in February's newsletter.

BRMEC5

On 27-28th May we hold the Biomedical Research into ME Colloquium 5 research meeting. Chairing the meeting again will be the charity's advisors Dr Ian Gibson and Professor Jonathan Edwards.

Represented at the research meeting will be experts in the fields of neuro-inflammation, immunology, allergy, rheumatology, neuroimaging, clinical trials, virology, gut immunology, transplant immunology, visual processing, epidemiology, biochemistry, microbiology, oncology etc.

Representatives from sixteen countries have been invited to participate in BRMEC5.

We believe in our model of biomedical research meetings - based on sharing knowledge, experience and data between international biomedical researchers and organisations and initiating new collaborations and new research opportunities.

Ten years of researchers, clinicians, healthcare professionals, patient groups, patients and the media being able to discuss, network and debate.

Read More

OPPORTUNITIES FOR SPONSORSHIP

Invest in ME is run by volunteers. The charity therefore welcomes support from companies, organisations, support groups and individuals to make the IIMEC10 International ME Conference 2015 events a success.

To enable us to provide the best research colloquium and conference possible we welcome donations or sponsorship.
We offer a number of opportunities to promote your organisation at our conference, including those listed below. To discuss further then please contact us. –

- ✓ Headline sponsorship
- ✓ Sponsorship of the BRMEC5 Colloquium - a 2 day research meeting on 27-28th May
- ✓ Sponsorship of the IIMEC10 pre-conference dinner evening
- ✓ Sponsorship Drinks reception at pre-conference meal
- ✓ Sponsorship of the costs of a presenter at IIMEC10
- ✓ Delegate material sponsorship including lanyards, delegate bags, pens
- ✓ Exhibition table at conference
- ✓ Corporate inserts in delegate packs
- ✓ Advertising in conference Journal
- ✓ ME groups can also “sponsor” a healthcare professional to the conference via our reduced rates (no charge to the group)

Please note that sponsorship decisions are at the discretion of trustees of the charity.
Thank you!

http://www.investinme.eu/#sponsors

Invest in ME Research Update

Our Advisory Board met in November and discussed the status of our projects, future research and the upcoming IiME research colloquium and conference events.

There are a number of logistical matters to be worked out as we continue to try to expand the research base and it requires a fair amount of effort from the charity to create the opportunities we feel are required to build on our strategy.

We continue to try to raise funds for future research projects and are happy to accept pledges as well as actual donations.

Having gained a solid foundation of biomedical research we need to aim to continue these future projects and have been working with the researchers to support collaborative efforts across disciplines and between different organisations.

Rituximab Project

The charity has just paid UCL for the preliminary B-cell study which our advisor and the research team decided was necessary prior to any rituximab clinical trial proceeding.

The preliminary B-cell study is still ongoing and Dr. Jo Cambridge will be discussing the study and progress at the conference in May.

One of the key areas for IiME is to improve education. We have several medical students intercalating on projects that the charity is funding or participating in summer schools which focus on these projects.

A young researcher, Fane Mensah, who has been working on the IiME funded B-cell biology project at UCL provided the following personal view of ME research - "ME/CFS – Through The Eyes of a Young Researcher" - click here.

Rituximab Web Site

UK Gut Microbiota Research Update

After a very long period of going through the complex ethical approval process the UEA/IFR team have now begun taking samples for the UK gut microbiota project.

We will have an update at the IiME conference in May.

UK Gut Microbiota Project Page

> "Navena a fourth year medical student soon to begin her MRes [this is one of the MRes positions being funded by Invest in ME], will be attempting to detect an antibody against a gut commensal found in the microbiota that also has the ability to cross-react with proteins found in nerves. The aim here is to determine if alterations in intestinal barrier function and/or microbiota firstly, exists in ME/CFS patients and secondly, whether there is an interaction between microbe-driven inflammatory responses and neuronal proteins."
>
> - Daniel Vipond, UK Gut Microbiota Research Update

FUNDING AND AWARENESS

Just a short collection of events to raise funds and awareness of biomedical research into ME.

Walk for ME

Luke Remnant has launched Walk for ME 2015 which has already raised an enormous amount for ME. The facebook page for the current event is is https://www.facebook.com/events/1529930570598706/?ref=2&ref_dashboard_filter=upcoming

There are many IiME supporters taking part in the Walk for ME event such as Kara Spencer's carers, Ati O, Charlie Hickman, Dave and Tanya Mawer, Kirsty Turner, Luke Remnant, Rachel Green, Taokat Fogger and Walkies for ME. Their pages can be found at https://www.justgiving.com/teams/walkforme2015.

2015 miles in 2015

Chris Croshaw is running 2015 miles in 2015 to raise awareness of ME and also hoping to raise funds for IiME. Chris' fundraising page is at https://www.justgiving.com/Chris-Croshaw5

Brighton Half Marathon 2015

Alana Stewart is running the Brighton Half Marathon 2015 on 22 February. Alana's event page is at Fundraising page: http://www.justgiving.com/Alana-Stewart1

Birthday Challenge 2015/16

Corinne Baker has set up a Birthday Challenge 2015/16 fundraising page at http://www.justgiving.com/KittySparkles

Thames Path Challenge 2015

Jenny Dean is taking part in the Thames Path Challenge 2015. Jenny's fundraising page is at http://www.justgiving.com/TeamBattleBorn

Twilight Colourthon

Gabby Broadbent and Charlie Hickman are taking part in Twilight Colourthon. Their fundraising pages are at http://www.justgiving.com/Gabby-Broadbent and http://www.justgiving.com/Charlie-Hickman

Sheffield Half Marathon

Luke Shepherd is running the Sheffield Half Marathon in April and his fundraising page is at http://www.justgiving.com/Luke-Shepherd3

Tough Mudder South West 2015

Zoe Miles will be taking part in Tough Mudder South West 2015 in August. Her fundraising page is at http://www.justgiving.com/zoe-miles

A big thank you to Eva Oschlak, group ambassador for Newry & Mourne ME Support Group, and to her friends Kristin and Neil who very kindly donated £200 for biomedical research.

Hay Green has sold books in support of IiME and recently she was making calendars and donating £2.50 for each one she sells to IiME. Thank you Hay.

We would also like to thank our supporters and the **Galaxy Hot Chocolate Fund** for the award of £300 - more details here

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PARLIAMENT and ME

> ***"I want first to put on the record that we accept the World Health Organisation's classification of ME as a neurological condition of unknown cause".***
>
> *- Gillian Merron, Minister of State (Public Health), Department of Health Adjournment debate on ME 23rd February 2010*

Another slot in our rituximab matrix was filled at the end of 2014 by a very generous donation from **FM-CFS Canada** - click here.

IiME chairman Kathleen McCall wrote –

"This is the second occasion that **FM-CFS Canada** has donated to the trial fund and enforces the international dimension of the trial and demonstrates how important international collaboration is for progress for ME/CFS.
The very generous donations from FM-CFS Canada help enormously in continuing this venture and ensuring that people with ME/CFS and their families all over the world can look forward with hope for a better future."
The rituximab Matrix is here.

We have so many to whom we would like to express our thanks but know that we cannot reach all who have helped and we hope all will understand our appreciation for all the efforts made to allow biomedical research into ME to be created.

We aim to reply to all donors directly, where possible, or to the Just Giving fundraising page owners.
If we have not reached all who have donated to Just Giving pages or various fund-raising campaigns then we apologise.

We hope our new web site will give a better view of fundraisers and their efforts.

Our supporters are not confined to the UK.
This is an international problem and we are lucky to have supporters in many countries around the world.

Occasionally we receive some feedback also - which is very much appreciated - the most recent coming from Sweden –

"many thanks for your ceaseless, hard and infinitely valuable work, and extra special thanks for your fabulous and brave p2p comments!"

Thanks again to all the great supporters of IiME who have set up Just Giving pages to raise funds for our work.

Please support and publicise these events as much as possible.
Even if you cannot afford to donate you can help by highlighting these great efforts/events and teamwork

http://www.justgiving.com/investinm-e

European ME Alliance

The European ME Alliance currently has 13 members – for thirteen European countries.

EMEA is now expanding and the first Associate Member is about to join EMEA thus strengthening the Alliance and creating more opportunities for ME research.

> *“ History of science teaches us that scientific endeavour has often in the past wasted effort in fields with absolutely no yield of true scientific information…Of course, investigators working in any field are likely to resist accepting that the whole field in which they have spent their careers is a ‘**null field**’ ”.*
>
> ***The day is surely approaching when it will be conclusively shown that the psychosocial lobby have spent their ME/CFS careers in a “null field”.***
>
> *- Margaret Williams BMJ Responses*

Invest in ME

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 and uses innovative and positive ideas to raise awareness– see http://ldifme.org/

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

Invest in ME

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IS THIS WHERE THE CAUSE of ME LIES?

UK Gut Microbiota Project II

We'd like to find out!

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 UK 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)

www.investinme.org email: info@investinme.org

£129,000

Target = £200,000

Invest in ME Research – Let's Do It!

ukrituximabtrial.org

ldifme.org

£367,000

Target = £450,000

Invest in ME Research – Let's Do It!