

Invest in ME (Research)

New Year

Message 2016



A New Decade of Invest in ME Research

www.investinme.org



From Invest in ME

Happy New Year

A New Decade in Invest in ME
Research begins.

2016 – a year where change for a better future for ME patients and their families can be realised.

We believe there have been promising signs over the past few years that permanent change is occurring – much to the credit of IiME supporters.

Supporters of IiME have continued to show resilience and integrity in their attitude and actions as, together, we influence how ME is treated and researched.

Much of the blame for the lack of progress in the last decade must be placed with those in the Medical Research Council who have been responsible for selecting applications to fund over the last 10-15 years and who have allowed the ignorance about ME to be maintained due to their funding of flawed research or of limiting funds given to research into ME.

The false impression of progress attempted by so-called MRC "expert" panels and its offshoots may fool some yet little has actually changed for ME

patients from this main funder of research thus allowing the NHS to be influenced mainly by those who promote the psychosocial paradigm of ME, a paradigm which considers ME as a medically unexplained or functional syndrome rather than a true physical disease as stated by the IOM report that was published in 2015.

Without the policy-based evidence making and the repeated rejection of valid biomedical research applications then it would not be possible for healthcare staff to be misinformed.

Nowhere has this been more clearly exemplified than in the flawed and increasingly absurd PACE Trial which has influenced healthcare in UK and abroad.

"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."

IiME Jan 2015

The PACE trial has been debunked as not just a disgraceful waste of scarce research funding but also totally flawed in so many areas that a retraction will be the only course of action left in 2016 – a testament to what not to fund and how not to conduct a trial.

It seems clearly likely that those in the MRC who have been responsible for ME will continue to maintain their silence on the matter whilst other organisations will be dragged into the quagmire where reputations will be damaged.

Yet accountability for the waste of years and funding by the MRC on a flawed approach to ME will be something that patients will need to demand as we see no prospect of any honorable actions from those responsible.

The task of overcoming years of irresponsible actions by those responsible for deciding research strategies and funding is not small.

But gradually this disease is finally getting correct attention and correct research.

Thanks to all of our supporters for the support and trust placed in the charity.

Our thanks to the [Let's Do It For ME](#) team for the enormous work they have performed and the service to the ME community which they have achieved through their tireless efforts to raise awareness and funds via positive and innovative campaigns

Despite enormous difficulties we are making things happen.

In 2005 Invest in ME was formed.

In 2006 Invest in ME registered as a UK charity.

So 2016 marks the tenth year of Invest in ME becoming a charity and as we enter a new decade for the way in which myalgic encephalomyelitis is perceived, managed, funded, researched and treated then we also enter a new decade of possibility and opportunity.

In February 2015 the charity reached a milestone of £1/2 million raised in 4 years and a new target has now been set for £1million by May 2016 (see our March on a Million campaign)

It is amazing to realise that next year will see our eleventh international ME conference take place in London.

It will also be our sixth biomedical research into ME Colloquium.

For eleven years we have been facilitating the interacting, discussion and collaboration between patients, researchers and clinicians.

Ten years ago Invest in ME was formed to make a change in how Myalgic Encephalomyelitis was perceived and treated in the media, by health departments and by healthcare professionals, and to educate, publicise and lobby regarding ME and the urgent requirement for public funding for biomedical research.

A decade of commitment to research, education and awareness has finally succeeded in opening up new areas of research.

A strategy of high-quality biomedical research has broken the mould of the past and a new decade now brings new and possibly decisive projects which will finally overturn the barren landscape of ME research which had been allowed to exist for too long.

Ten years ago the ME research landscape was different with no platform for regularly showcasing or encouraging biomedical research, and no funding or recognition of the need to fund biomedical research into this disease.

We mentioned last year that we can feel that real progress is underway – with the last ten years of effort by IiME and its supporters having forced real change. These have been the foundations upon which we can build a sensible policy toward ME.

The charity has two major high-quality research projects underway – possibly

the two most important research projects for the future of ME research in the UK – but certainly the most promising foundation for translational biomedical research into ME in UK/Europe.

This strategy has been augmented with education and participation in our research projects by medical students - enhancing theirs and their peers' education about ME and building a base for the next generation of researchers.

The charity has designed and facilitated the establishment of the European ME Research Group - a group of top European researchers who will collaborate and establish multi-site international biomedical research projects which will overturn the miserly funding being directed to ME research which has discouraged good research to be formulated or performed.

The charity is at the heart of European cooperation within the European ME Alliance involving 13 countries in Europe and with the potential to achieve so much.

The Invest in ME original strategy of bringing in researchers from other fields to

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help and improve biomedical research into ME has been successful and well worth the effort and cost.

Our conferences bring together patients, researchers, clinicians and healthcare

staff and allow knowledge and experiences to be shared – now for eleven years.

Our research colloquiums are bringing together high-calibre international researchers – concentrating on biomedical research - that can help us understand the cause/s and pathomechanisms of ME.

The charity's proposal for a Centre of Excellence for ME is possible to achieve and it has set a target which can be reached if enough support is given.

Due to imaginative and positive support such as the Let's Do It for ME campaign and thanks to dedicated supporters the charity enters a new decade which promises to transition all the efforts of the past ten years into benefits for all patients and their families - and also for healthcare staff.

All of this brings momentum which then spawns changes elsewhere - by influencing others, by interesting scientists and researchers in new research areas and establishing a change in how ME is perceived.

A lot is spoken about joining together and glossing over differences in how ME is perceived. But this is a false view and will achieve nothing but a fudged approach to ME which will ill serve patients and their families. Compromising on the future of ME patients simply risks returning to the failed scenarios of the past – and we will not do that!

As we look forward we will continue to seek change.

If a disease is well understood then all aspects of patient care may improve whilst cures and treatments are being developed.

Understanding of ME and finding the cause/s and pathomechanisms can only be achieved if research takes a clear

stand of ME being a physical illness as a starting point and everything else is consequential.

There are now enough clues, well presented over the ten years of IiME conferences that need to be followed up.

Clinical trials such as the phase III rituximab trial in Norway and the UK rituximab trial project, initiated and funded by IiME, give patients hope and make healthcare professionals take ME seriously even before the trials have begun or results published.

Even the awareness of ME patients being part of proper mainstream clinical trials makes a huge difference to the perception of this disease.

This we have witnessed already and it just highlights even more the waste of years due to the failed policies of the past.

Invest in ME have never had any doubt of ME being anything other than a physical illness and we do not believe there is sense or reason for mixing flawed psychosocial views of the disease with biomedical views under one umbrella.

We hope that our ten years of focused approach and engaging with researchers that have the skills to help solve ME is beginning to bring results and will continue.

This is a good time to be involved in ME research as we are at the beginning of making discoveries. We are optimistic for the future as patient power has made it possible for patients to show the types of research they want and need.

We believe we can look forward, and expect even more rapid progress in the future – directed by agents of change which have been or are being created.

The IIMEC11 conference and BRMEC6 research colloquium provide unique opportunities to begin this new decade

of conferences with an intent to resolve ME once and for all.

So In the UK we have a solid base of research created for developing our Centre of Excellence proposal.

In Europe a new European ME Research Group has formed to collaborate even more on research into ME.

Further afield two prominent reports (from NIH and IOM) in 2015 categorically established ME as a disease which needs massive changes in funding.

And for so many patients and their families this will not have come a moment too soon.

Happy New Year

The Chairman and Trustees

Invest in ME/Research



The work that we do.

Invest in ME (charity nr 1114035) transitioning to Invest in ME Research (charity nr [1153730](#)) was set up as an organisation by parents of children, carers and patients suffering

from myalgic encephalomyelitis (ME) in 2005 and became a charity registered with the charity commission in England and Wales in 2006. The charity raises funds for biomedical research, provides educational material, raises awareness, organises educational events and supports individuals with ME in distress.

ME is an underfunded and often misunderstood disease that causes a lot of poverty and hardship for patients and their families.

Invest in ME (Research) is run by volunteers with no paid staff and the trustees and volunteers have worked very hard over the past ten years or so to try to change attitudes toward patients suffering from ME and raise funds to initiate research that patients want and need.

The charity has managed to encourage others to join its efforts and in 2011 this led to a sister organisation 'Let's Do it for ME' campaign to being formed by three bed/housebound patients. They in turn have managed to use the social media very effectively to garner support the charity's work.

Invest in ME (Research) are a founder member and current chair of the European ME Alliance (EMEA), an umbrella organisation of 13 national charities. In 2015 EMEA joined the European Federation of Neurological Associations (EFNA) and became also represented on their board. This allows EMEA to take part in various events and working groups organised by EFNA and the European Brain Council.

What difference does the charity make?

Invest in ME (Research) want society to treat ME patients with respect, offer ME patients the same rights and

access to care, housing, education and benefits as any other chronically ill patients.

The charity is not afraid of speaking out and works for the benefit of patients.

The charity is passionate about its aims and objectives and does not give up when facing obstacles.

One of the charity's advisors, Dr Ian Gibson, is writing a book called 'Science, Politics and ME'. He is well placed to do so having been involved in a lot of the charity's and UK ME patients' struggles for proper recognition.

We are delighted to have been able to initiate a strategy of collaborative research at IFR/UEA and UCL and also at European level by establishing and facilitating the formation of the European ME Research Group (EMERG) which held its inaugural meeting in London in October 2015 and will meet up again in June 2016.

In 2016 we expect two more PhD students starting their ME projects at IFR/UEA and Fane Mensah has also become a PhD student at UCL - able to carry on his promising IiME funded B cell work which forms part of the rituximab project. First part of the B cell research was published in December 2015.

The community the charity works with and the challenges it is facing.

The ME community have had a very hard time with media misrepresentation of ME and incorrect information being promulgated by even major medical text books. This can result in family break ups and patients even being wrongly sectioned in psychiatric hospitals. The charity

gets calls for help in situations like these.

The way the charity tries to help and affect change is by organising educational events such as the annual IiME international conference and research Colloquiums, by providing up to date educational material about ME and engaging new researchers, and involving medical students in the research we facilitate and fund.

The past year 2015 has been an interesting one in that more and more scientists from outside the usual ME field have commented on the flaws of the so called PACE trial that promotes CBT and GET as moderately effective and safe treatments for ME patients. This turn of events was initiated by a series of articles on the flaws of the PACE trial written by journalist David Tuller and published by Professor Vincent Racaniello in his very popular Virology blog. Professor James C. Coyne joined in commenting and blogging about the issue and things have snowballed in a way that patients never imagined. Patients' voices have been finally heard by independent observers.

What strengths and opportunities does the charity see in the ME community?

Invest in ME (Research) proposed a model for an ME Centre of Excellence for ME to be established at the Norwich Research Park in 2010. The Let's Do It For ME (LDIFME) team of volunteers joined IiME in crowdfunding for the foundation gut microbiota project in 2011.

The first ME research project at IFR/UEA started in 2013 after the first fundraising target of £100 000 had been reached. This was a unique achievement by the UK patient community although funds were also received from the worldwide ME

community. The charity's crowdfunding success has encouraged the worldwide ME community to become more active in raising funds for research and has also been noticed by the Norwich Public and Patient Partnership in Research initiative. They used Invest in ME (**Research**) as an example of patients making a difference and in 2015 Invest in ME (Research) was invited to present at a Social Media conference in Norwich organised by IFR.

In 2014-2015 the charity funded two intercalating fourth year medical students from UEA medical school who took part in ME related research. A third medical student has started work for the term 2015-2016 assisted by the fundraising efforts of our supporters in the 2015 Big Give Christmas challenge. These schemes have proven to be very useful not only in assisting research but allowing young medical students to become involved in something new and exciting. They in turn influence their peers and help in education about ME.

Invest in ME's annual international conference attracts delegates from 15 different countries and it has become an event for networking and social gathering for patients, carers, researcher and healthcare professionals.

The next conference in June 2016 will be the charity's 11th public conference and 6th colloquium.

How can you best help Invest in Me?

The charity would love to have support for spreading information about our events and distributing material to healthcare professionals.

You can help by giving moral support or publicising other people's

fundraising efforts if you are not able to do anything yourself.

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>

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Support ME Awareness - Invest in ME Research



investinme.org

ldifme.org

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

**Small Charity
 BIG Cause**
 Support ME Research
 Invest in ME

New Total



£169,000

Target = £200,000

Invest in ME Research - Let's Do It!

Invest in ME Rituximab Research Fund

www.ukrituximabtrial.org



£469,000

Target = £520,000

Invest in ME Research - Let's Do It!