Invest in ME Research

Charity number 1153730

PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

Tel: 02380 643736   07759 349743

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

Invest in ME Research (IiMER) is a UK charity (charity number 1153730) established in 2006 (as charity Invest in ME/ IiME) to educate healthcare systems, the public and media about Myalgic Encephalomyelitis (ME or ME/CFS) and raise funds for fundamental biomedical research that would establish an understanding of the aetiology, pathogenesis and epidemiology of ME.

The charity has organised 13 annual CPD-accredited international ME/CFS conferences and 8 research colloquiums that have attracted delegates from 20 different countries to allow researchers, clinicians, patient groups and patients to learn about the latest research. The research Colloquiums are unique events that allow researchers to form collaborations and share experiences to advance research into this disease. [1]

The charity strongly believes in international collaboration in biomedical research into ME and has built up a community of international researchers who come together at our Colloquiums and Conferences. IiMER is the current chair of the European ME Alliance, an umbrella organisation of 15 national European patient groups and charities working together to improve awareness of ME and facilitated the establishment of a European ME Research Group (EMERG).

The charity initiated a proposal for a Centre of Excellence in Norwich Research Park in 2010 [2] which has been in the process of developing and which can form a hub for research in Europe – with links to other European and US research institutes.[18]
This proposal and the research at University of East Anglia (UEA)/Quadram Institute Bioscience (QIB) has been funded by the charity and its supporters with no help from government or other public bodies. There are currently four PhDs in Norwich studying the disease under the supervision of extremely qualified and experienced professors. The charity is also funding another PhD at UCL.

IiMER has not been invited to be a stakeholder in any debate regarding ME in Scotland but the charity has many Scottish supporters. Some years ago the charity sent 25 GP packs to Scottish surgeries and practices containing relevant information about correct diagnostic criteria, CPD-accredited Conference DVDs, information articles and other leaflets which can inform healthcare staff and patients in an attempt to educate and inform of biomedical research into ME [3].
The charity has also helped individual patients in Scotland by providing letters of support in cases where patients were being disbelieved by their GPs or had problems with insurance companies
We therefore feel compelled to comment.

ME is a grossly underfunded and understudied disease and deserves proper research to be carried out to discover the aetiology.
However, for far too long the ME field has been dominated by the so called biopsychosocial (BPS) school of thought that theorises that ME is a behavioural illness that can be remedied by simplistic methods of cognitive behaviour therapy (CBT) and graded exercise therapy (GET) [4].

This approach has done nothing to remove the stigma about ME and the serious lack of medical help for ME patients. On the contrary, many patients have been made worse by flawed BPS ideology regimes due to the current NICE guidelines recommending these therapies.

It is now evident from the disastrously wasteful PACE trial that CBT and GET did not work for ME/CFS or any of the loosely defined fatigue patients taking part in the trial. [5,6,17]
This wastes valuable healthcare funding in therapies that patients do not want and which do not help them - funding that could be used for genuine mental health conditions.
The situation arises where patients are constantly pitted against doctors who are forced to use flawed NICE guidelines or healthcare providers who continue to remain ignorant or apathetic toward ME. This all adds to the stigma for ME patients.
ME patients do not want CBT or GET. Listen to them!

Patients, who have to deal with disability insurance companies when unable to carry on working due to ME, often do not have any choice of taking part in these therapies even if they are made worse by them. This is despite NICE's nuances that a patient can choose not to undertake these therapies. In extensive correspondence with NICE Guidelines director, Professor Mark Baker [7], IiMER has established that NICE consider the existing guidelines as unfit for purpose and recognise that CBT and GET do harm to patients.

Research into ME needs to concentrate on the fundamental research – as the Centre of Excellence being proposed and developed by Invest in ME Research is doing.

Scottish ME patients deserve proper care based on good science and up-to-date education. The Chief Medical Officer of Scotland should be far more concerned with the failings in care for ME patients (the English CMO has long since totally abrogated any responsibility in this area).

There is a serious lack of qualified consultants in the UK who understand ME and GPs are often unable to deal with the complexity of ME by themselves. This often leaves ME patients to fend for themselves and they often exit the healthcare system.

It is time to take a fresh, new approach and help ME patients regain their health rather than carry on with an approach using the BPS theories for treatment that do not work and that cost a great deal of money.

The Scottish government likes to claim that it enforces transparency. It should therefore enforce this in dealing with ME by avoiding the coercion of patients into taking deleterious "treatments".
The problem will not go away just because of the hype around soundbite-healthcare remedies.

There is a great deal of international concern regarding the lack of an evidence base for CBT and GET for ME. So much so that the US CDC have removed these recommendations from their website and the US Agency for Healthcare Research and Quality (AHRQ) has downgraded the evidence for these therapies due to the criteria being used for CBT and GET research [8].
The Finnish Valvira agency has also removed CBT and GET as recommendations [9].
The US Institute of Medicine (IOM) report that was published in 2015 [10] reviewed all the ME/CFS research literature and described the intolerance of any form of exertion (physical or mental) by people with ME. The IOM report was a major indictment of negligent MRC/NIH/CDC policy, highlighting the way that research, treatment, and information about ME have been totally misrepresented over the last generation by false funding policies, flawed research and vested interests.

The reason for a lack of proper research is purely due to the manipulation and influences of the BPS lobby on government health departments, medical research councils and NHS which has resulted in the limited funding available being given to BPS protagonists. The prime example of this was the PACE Trial [11] – a £5 million pound travesty of science which is now seen as an example of how not to do research. Questions have also been raised in parliament regarding possible fraudulent activity relating to the trial.
This bias has stifled research funding on the fundamental research into the disease and has led to lack of any real progress in encouraging researchers into this field.
This can be easily demonstrated by the experiences of Invest in ME Research having funded over £400k of research in the last 5 years that has encouraged researchers and brought new researchers to enter the field.
The charity’s view is that the establishment of our Centre of Excellence for ME model will provide the best hope for studying the disease systematically and will help establish good basic standards.
Research is accumulating rapidly and the most reliable sources are recent comprehensive summaries, known as systematic reviews, of all the research undertaken to date.

Regarding the petition.

Investing in biomedical research

It is obvious by now that funding for biomedical research into ME needs to be increased.

At a recent parliamentary debate IiMER submitted information which proposed that £20 million per year be spent on biomedical research into ME for five years, This is a small amount in comparison with the estimated cost to society of ME of having a presumed 250,000 ME patients and many more carers occupied with providing support for these patients.

Although based in Norwich Research Park the Centre of Excellence is creating a strategic approach to developing biomedical research into ME and work will with other research institutes in a hub and spoke model. By working with the centre in Norwich Research Park then Scotland could provide a real boost for research into ME in Europe.

Ensuring healthcare professionals’ training and education materials reflect the latest scientific evidence

Education is probably the best and easiest thing that could be done in the short term as this could have a direct benefit on patients by removing the stigma and misinformation and allow patients to be properly examined, diagnosed and entered for research.

There is a need for experienced clinicians that can oversee this work.
The aim now should be to establish a speciality that owns ME/CFS or makes ME/CFS a speciality in its own right – and this will not be psychiatry.
These specialist consultants would not only validate patients and allow some measure of service to be enabled within the NHS. They would, importantly, be able to work together with researchers and join up the Centre of Excellence approach suggested by IiMER.

Education of medical students and GPs is being performed. The charity has funded medical students to participate in research by intercalating in their fourth year of medical studies.
Education, especially of medical students, should be an objective that is given high priority.
The aim should also be to interest new researchers to enter the field.

Invest in ME Research has initiated the Thinking the Future (TtF) conference [12] – an event for young/early career researchers who are involved in or would consider entering the field of ME biomedical research. The charity arranged the first of these in London in 2018 and plans to arrange others in Europe.
To facilitate young/ECR Scottish researchers Invest in ME Research will offer up to ten places at its TtF 2019 event in in May in London to young/ECR researchers in Scotland. This will present a chance for Scottish researchers and medical students to mix with other young/ECR researchers.

Providing specialist care for patients and discontinuing the harmful treatments of graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

The UK National Health Service (NHS) is currently wasting a huge amount of funds in giving these failed therapies to ME patients which are either useless, or deleterious to the health of ME patients. More importantly, these therapies are rejected by patients and, at a time where health services such as the NHS needs all the funding it can get, there is no sense in wasting resources or funds like this by any health service.

Even the most recent view of CBT and involvement of psychiatry for ME patients determines that "claims of efficacy of multidisciplinary rehabilitation treatment and cognitive behaviour therapy for chronic fatigue syndrome/myalgic encephalomyelitis are misleading and not justified by their results." [13] Scottish patients deserve better, as do all ME patients. As there are no proven effective treatments yet very severely ill patients urgently need palliative care in an understanding environment and definitely not rehabilitation.
There are lessons to be learned from the past decades of mistreatment of ME patients due to ignorance and corrupt influences.

Correct and early diagnosis is crucial. It is not in anyone's interest (neither that of patients nor of healthcare professionals) to try to fit a large heterogeneous group of patients into a care pathway that has no good treatment/management evidence. This lead to missing diagnosing a serious or rare condition that may take years to develop and which does not show up in early routine tests. Who takes responsibility when patients are encouraged to downplay their symptoms and rely on psychotherapists and CBT therapists to manage them with various stress reduction and life style management techniques? It would be quite appropriate in these circumstances for substantial litigation be taken against the service provider or the agency who force CBT and GET on to patients if those therapies eventually cause harm to the patient.

The IOM report makes a major point - "Key to this effort will be the continued positioning of ME/CFS as a legitimate disease that occurs in both children and adults and should be properly diagnosed and treated." The Scottish authorities would help by emphasising that ME/CFS is a serious physical illness and that in itself leads to health care providers taking a correct attitude toward these patients despite there being no cure or effective treatment being available yet.
Just informing patients to avoid overexertion in the early stages of their diagnosis might make a huge difference in the outcome of the patients' long-term health.

For a review of the status of ME we draw your attention to IiMER's status of ME [14]
In the UK the CMO report of 2002 [15] produced seven recommendations. None have been actioned.

Finally, we would ask you to read a recent letter sent to Invest in ME Research that clearly illustrates the failure of UK governments and health departments and the MRC in dealing with ME.
It comes from a patient who was in the same union as most of MPs are in. This patient's experience could be any civil servant's or healthcare professional's experience if they find themselves with ME.[16]

REFERENCES

1. Conference/Colloquium website www.investinme.eu
2. Centre of Excellence for ME www.investinme.org/ceindex.shtml
3. http://www.investinme.org/IIMER-Campaigning-News-Oct12-05.shtml
4. http://www.investinme.org/Documents/Fact%20Sheets/Invest%20in%20ME%20Research%20-%20Flaws%20in%20BPS%20Theory%20for%20ME%20Fact%20Sheet.pdf
5. White P.D., Goldsmith K., Johnson A.L., Potts L., Walwyn R., Decesare J.C., Baber H.L., (...), Sharpe M. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): A randomised trial (2011) *The Lancet*, 377 (9768) , pp. 823-836.
6. http://www.investinme.org/Documents/Fact%20Sheets/Invest%20in%20ME%20Research%20-%20Flaws%20in%20BPS%20Theory%20for%20ME%20Fact%20Sheet.pdf
7. IiMER correspondence with Professor Mark Baker of NICE http://www.investinme.org/IIMER-Newslet-1801-01.shtml
8. http://www.investinme.org/Status-of-ME-References.shtml#27
9. http://www.investinme.org/Status-of-ME-References.shtml#44
10. https://www.ncbi.nlm.nih.gov/pubmed/25695122
11. http://www.investinme.org/Status-of-ME-References.shtml#31
12. http://www.investinme.eu/thinkingthefuture.shtml
13. http://www.investinme.org/Status-of-ME-References.shtml#49
14. Status of ME 2018 http://www.investinme.org/Documents/Fact%20Sheets/Status%20of%20Research,%20Treatment%20and%20Perception%20of%20Myalgic%20Encephalomyelitis%202018.pdf
15. http://www.investinme.org/Status-of-ME-References.shtml#4
16. Communication from a patient regarding CBT and GET and disability benefits http://www.investinme.org/IIMER-Newslet-1801-01.shtml
17. Carolyn Wilshire, Tom Kindlon, Alem Matthees & Simon McGrath (2017) Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial, Fatigue: Biomedicine, Health & Behavior, 5:1, 43-56, DOI: 10.1080/21641846.2017.1259724
18. Quadram Institute/Centre of Excellence for ME https://quadram.ac.uk/targets/me-cfs/