



A UK Centre of Excellence for ME

Turning the Dream into Reality

Executive Summary for MPs

UK Charity Invest in ME Research

A UK Centre of Excellence for ME

Executive Summary for MPs

This is a summary of the status regarding UK charity Invest in ME Research's development of a UK Centre of Excellence for Myalgic Encephalomyelitis (ME) based in Norwich Research Park, Norfolk, UK.

STATUS UPDATE June 2018

Background

- A seriously inadequate standard of medical care for ME patients in UK and Europe
- Very little and very fragmented biomedical research into the disease and no strategy of research had been formed
- Confusion between ME and chronic fatigue has led to unscientific research and ineffective treatments being offered which are deleterious to the health of people with ME – treatments which federal agencies in USA have now stopped recommending
- Medical professionals lack understanding of, and training in, ME – a serious risk of mis-diagnosis and missed diagnoses exists with potentially damaging consequences
- There are sparse consultant-led specialist services available for ME patients
- Medical students are taught very little or nothing about ME from a curriculum which uses flawed or out of date information about ME
- ME has been identified as both a highlighted area and a high priority by MRC – yet MRC has until now failed to fund adequate biomedical research into ME
- ME is leading cause of long-term absence from school due to sickness for students and teachers
- ME is recognised by the Department of Health as a chronic neurological illness yet official treatments/management are aimed at changing patients' false illness beliefs
- In 2015 The USA Institutes of Medicine (IOM) recognised ME as a serious, chronic disease after conducting a major review

- The usual estimate for prevalence in UK is 200,000 – 250,000 patients, with 25% being children. However, at a recent meeting convened by Invest in ME Research the Chief Medical Officer of England stated that they did not know the prevalence of the disease in the UK and admitted to knowing little about the disease

Project Outline

- A UK Centre of Excellence for ME, with the hub based in East Anglia, within the Norwich Research Park, utilising and based on university and institute facilities and resources
- A hub of scientific and clinical excellence for ME within Europe
- The research arm to be funded initially by private/charitable donations leading to applications to major public research funding bodies
- Clinical diagnosis and treatment arm to be funded within NHS using existing or augmented services
- Links are established with other UK, European and international institutes to collaborate on biomedical research projects to determine cause(s) and develop treatments for ME

Service Commissioning

- GP referral, via normal NHS channels
- A consultant led service that links with GPs with special interest
- Treatment of patients to be based on sound scientific evidence
- A hub and spoke model: dissemination of expert knowledge to GPs and ME clinics nationwide and internationally
- Out of area referrals included which would generate income
- Training opportunities for medical students and other consultants, nurses etc.
- Development of a unique training establishment is made possible
- A clinical pathway established for ME
- A clinical/academic specialty for ME to be developed

Benefits

- Unique opportunity to establish European hub of scientific and clinical excellence in Norwich Research Park
- Attraction of international interest and research funding to UK
- Early and correct diagnosis of patients which would apply for all UK patients
- Establishment of standard protocols for effective diagnosis
- Establishment of clinical trials
- Formation of a strategy of biomedical research based on international collaboration which will increase capability and funding possibilities
- Development of effective treatments, leading to highly significant public savings in benefits and healthcare
- Combining treatment and research (clinical and basic) provides the best option for progress in knowledge and education
- Hub and spoke model to address seriously inadequate levels of clinical service for ME in UK
- Development of network of domiciliary services to support severely affected patients (currently seriously neglected by the health service)
- Enhancing education of medical students by actively involving them in research into ME and creating up to date educational modules which truly reflect the biological basis of the disease
- Establishment of information centre for ME which would serve patients, carers, the public, politicians, academic and healthcare organisations and the media with correct and up-to-date information about ME
- Financially viable – UK Centre of Excellence can start small and grow as further funding becomes available

Current Status

- All elements of the centre model exist and are ready to be integrated, with the exception of a lead ME consultant speciality. The charity has been in discussions with the CCGs, university and Norfolk and Norwich University Hospital
- Currently a leading NHS consultant in Surrey has provided accurately diagnosed patients for research purposes.

- A Foundation project at Quadram Institute Bioscience/UEA examining the gut microbiota in ME patients started in October 2013 and is continuing
- There are now four PhDs performing research into ME at Quadram Institute Bioscience with help from University of East Anglia
- The charity is also continuing to fund a PhD student at University College London and has provided substantial funding to biomedical research at UCL since 2014
- Several medical students have been funded by the charity to intercalate in their medical degrees and assist in the research projects. The charity will continue to do this with more already planned
- A five-year plan has been developed to form a sustainable strategy of biomedical research involving international collaboration
- Collaboration is already underway between the UK Centre and researchers/institutes in UK, Europe and USA.
- Such collaborative efforts will maximize research speed and efficiency
- The creation of The European ME Research Group (EMERG) has opened the possibility of a European-wide collaboration which seeks national and EU funding
- The Quadram Institute Bioscience is entering a new £80 million building with medical school and clinical trials facilities in summer 2018
- Clinical trials able to commence there
- The NIH has endorsed the charity's plans for a centre

Expansion of Scope

- As increased funding is obtained then further expansion of the scope of the centre hub may be made with further international collaborations and more advanced research. The inaugural meeting of The European ME Research Group (EMERG) has opened the possibility of a European-wide collaboration that seeks national and EU funding.
- New services may be developed for patients based on a translational biomedical research model and be extended across the country.

Professor Ian Charles of the Quadram Institute has opened two of the last four Invest in ME Research International ME Conferences in London -

Invest in ME Research

- A UK charity funding, facilitating and campaigning for biomedical research
- Founder member and current Chair of European ME Alliance
- Has organised thirteen annual CPD-accredited international ME conferences in London
- Has organised eight annual international CPD-accredited ME research Colloquiums in London
- Allied to a patient-led campaign called Let's Do it for ME to crowdfund for Invest in ME Research
- Has initiated and funded UK gut microbiota project to study ME at UEA/Quadram Institute Bioscience
- Has initiated and funded research projects at UCL
- Holds worldwide contacts with ME organisations, physicians and researchers
- Has initiated and facilitated creation of The European ME Research Group (EMERG) – a collaboration of leading European researchers
- The charity has a highly-qualified scientific advisory board and is actively looking at complimentary and collaborative projects around the Centre of Excellence for ME, which will increase the research knowledge base and translate research into treatments.

NIH ANNOUNCEMENTS

Recently the National Institutes of Health in USA has awarded funding for four Centres in USA to carry our research into ME. The NIH has already credited the charity with a sound and visionary idea with our Centre in Norfolk and we have the opportunity to lead Europe in developing this Centre to become a worldwide focal point for biomedical research into this disease and bring hope back to patients' lives. The NIH news validates the vision of Invest in ME Research's approach since 2010.

Further Research

The charity has already made a five-year plan to seek funding for this development in Norwich Research Park and is working with Quadram Institute Bioscience on further ideas to develop this Centre. We have already secured the first year's targets in terms of research capacity.

Invest in ME Research is therefore asking for support from MPs to engage actively with this project with a view to securing the final, and vital, elements of the UK Centre of Excellence for ME and create a future whereby people with ME may be given back their lives.

Further details:

More information from the following links –

- **Research** <http://www.investinme.org/research>
- **Centre of Excellence for ME** <http://www.investinme.org/centre>
- **Fundraising for liME Research** <http://www.investinme.org/fund>
- **Conference/Colloquium** <http://www.investinme.eu>
- **Centre of Excellence web site** <http://www.cofeforme.eu>
- **Advisory board** <http://www.investinme.org/IIMER-ab.shtml>
- **Let's Do It For ME** <http://lidifme.org>

Invest in ME Research

Email: info@investinme.org
Telephone: 02380 643736 or 07759 349743

Web site: www.investinme.org



FAST TRACKING SOLUTIONS FOR ME



of Excellence for ME

investinmeresearch.org

Let's  **It!**

Myalgic Encephalomyelitis (ME) is a serious, chronic neurological disease. UK Charity Invest in ME - Research (IMER) are establishing a Centre of Excellence for ME - a hub for research activity in Europe - enabling a strategy of high-quality biomedical research projects to follow, coordinated and collaborating with other institutes. Please support our *C of E for ME*. Let's Do It for ME. Let's C research into ME.

See <http://www.investinme.org/research> #CofEforME #LetsCresearch @LetsDolt4ME

Invest in ME - Research (UK charity nr. 1153730)

www.investinme.org

email: info@investinme.org