

# **A UK/European Centre of Excellence for ME**

**Status of Development of  
Research into  
Myalgic Encephalomyelitis (ME)**

**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 the work of UK charity Invest in ME Research in developing a UK/European Centre of Excellence for Myalgic Encephalomyelitis (ME) based in Norwich Research Park and in facilitating and initiating international collaboration in a common research strategy for ME.

### STATUS UPDATE February 2020

## Invest in ME Research

- Is a UK charity funding and facilitating biomedical research into ME
- Is a founder member and current Chair of European ME Alliance
- Has organised fifteen annual CPD-accredited international ME conferences in London
- Has organised ten annual international CPD-accredited ME research Colloquiums in London with thirty major research institutes, organisations and agencies from around the world regularly attending, including NIH and CDC.
- Is allied to a patient-led campaign called Let's Do it for ME that crowdfunds for Invest in ME Research
- Has raised almost £1 million for research into ME
- Has funded high-quality biomedical research including investigations into links between ME and gut microbiome at University of East Anglia/Quadram Institute
- Has initiated and funded research projects at UCL
- Holds worldwide contacts with ME organisations, physicians and researchers
- Has initiated and facilitated the creation of the European ME Research Group (EMERG) – a collaboration of leading European researchers
- Has initiated and facilitated the creation of and the European ME Clinicians Council (EMECC) – a collaboration of leading European clinicians
- Is actively facilitating complementary and collaborative projects around the Centre of Excellence for ME, which will increase the research knowledge base and translate research into treatments.

## **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 improper treatments being offered.
- Medical professionals lack understanding of, and training in, ME – a serious risk of misdiagnosis and missed diagnoses exists with potentially damaging consequences
- There are sparse 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 a highlighted area by MRC – yet MRC has failed to fund adequate biomedical research into ME and seemingly is continuing to fail to provide a fair and level-playing field for potential applicants for research funding
- ME is a 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 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

## **Proposed Solution**

- A UK/European 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
- 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 established with other 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 a 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 being integrated, with the exception of a lead ME consultant speciality. The charity has been in discussions with CCGs, university and Norfolk and Norwich University Hospital
- Together with the Quadram Institute the charity is funding a Clinical Fellowship for a young GP to spend a year with the Quadram Institute to become acquainted with the research and then act as a clinical champion for the research into ME in the community of GPs.
- A leading NHS consultant in Surrey has provided accurately diagnosed patients for research purposes. Now the major ME/CFS Clinic in East Anglia, with 1800 patients, will provide patients for research.
- The charity has funded one PhD student at University College London and has provided over £200,000 of funding for biomedical research at UCL.
- A Foundation project at the Quadram Institute/University of East Anglia examining the gut microbiota in ME patients started in October 2013 and completed in 2019.
- With University of East Anglia the charity continues to fund three more PhDs who are currently performing research at the Quadram Institute.
- There are now four PhDs performing research into ME at Quadram Institute.
- The charity has initiated the concept of a European cross-site studentship for ME to encourage European collaboration and is funding a student who will be working with a Swedish institute.
- Several medical students have been funded by the charity to intercalate in their medical degrees and assist in the research projects.
- A five-year plan was 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 and Europe.
- Such collaborative efforts will maximize research speed and efficiency
- The charity initiated the creation of The European ME Research Group (EMERG) and this has opened the possibility of a European-wide collaboration which seeks national and international funding

- The charity also initiated the European ME Clinicians Council (EMECC) to improve clinical expertise on ME in Europe and provide collaborative foundation to assist researchers.
- The Quadram Institute entered a new £80 million building housing food and gastroenterology researchers and clinicians under one roof in 2019
- This year Invest in ME Research has pledged over £1/2 million for new research in Norwich Research Park, on top of the substantial amount already raised and used to fund research.
- A clinical trial for ME, funded by Invest in ME Research, is about to commence at the Quadram Institute in 2020.
- The NIH has endorsed the charity's plans for a centre of excellence and is currently funding three in USA, in a similar model to the charity's vision.

### 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 recent meetings of the European groups, EMERG and EMECC, have opened the possibility of a European-wide collaboration that seeks national and EU funding.
- New services can be developed for patients based on a translational biomedical research model and be extended across the country.
- This will potentially save billions if treatment can be found for this disease.

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

Invest in ME Research is therefore asking for support from MPs to engage actively with this proposal and strategy 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.

### Recent Announcements

In early 2020 both Quadram Institute and Invest in ME Research have had press releases.

These cover the funding pledge by the charity and news of the clinical trial and joint UK-Swedish research studentship.



## UK Centre of Excellence for ME

In February 2020 the charity and the Quadram Institute held a public engagement event in Norwich to present the current research and clinical trial.

1. UK Charity Pledges £500,000 for Research into ME in Norwich Research Park  
<https://quadram.ac.uk/uk-charity-pledges-500000-for-research-into-me-in-norwich-research-park/>
2. Meet the researchers behind a new trial into ME  
<https://quadram.ac.uk/meet-the-researchers-behind-a-new-trial-into-me/>
3. Event introduces the RESTORE-ME trial  
<https://quadram.ac.uk/restore-me-trial-event/>

### Further details:

More information from the following links –

- **Parliamentary Debate 2019** <http://investinme.org/2019debate>
- **Status of ME 2018** <http://investinme.org/2018status>
- **Research** <http://investinme.org/research>
- **Centre of Excellence for ME** <http://investinme.org/centre>
- **Fundraising for liME Research** <http://investinme.org/fund>
- **Conference/Colloquium** <http://investinme.org/conference>
- **Centre of Excellence web site** <http://investinme.org/centre>
- **Let's Do It For ME** <http://lidifme.org>

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**of Excellence for ME**

*[investinmeresearch.org](http://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)

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