



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

### **Executive Summary for MPs**

This is a summary of the status regarding Invest in ME Research's proposal for a UK Centre of Excellence for ME Research and Treatment with the hub based in Norwich, Norfolk, UK.

**STATUS UPDATE May 2017**

## **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 and deleterious therapies being offered
- Medical professionals lack understanding of, and training in, ME – a serious risk of mis-diagnosis and missed diagnoses
- Medical students are taught very little about ME from a curriculum which uses flawed or out of date information about ME
- ME identified as both highlighted area and high priority by MRC – yet MRC has 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

## **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
- 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
- Links to be 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

## 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
- 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
- Savings on existing consultant referrals and staff - ME examination focused in one area
- Establishment of information centre for ME which would serve 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 that the charity has been progressing in discussions with the CCGs, university and N&NUH hospital
- Currently an NHS consultant in Surrey has provided accurately diagnosed patients for research purposes.
- A Foundation project at Quadram Institute/UEA examining the gut microbiota in ME patients started in October 2013 and is continuing with three more PhDs starting in September/October 2016 and a further PhD student starting in autumn 2017.
- B-cell research, as part of a UK rituximab clinical trial project, began at UCL in 2014 and continued with a PhD and a student being funded.
- A senior research associate is being employed to help formulate the UK clinical trial of rituximab with collaboration already established with the Norwegian researchers at Haukeland University Hospital in Bergen who are conducting a Phase III multi-centre clinical trial.

- Several medical students funded by the charity have been intercalating in their medical degrees and we will continue to do this with more already planned
- A five-year plan has been developed to form a strategy of research involving international collaboration and 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 entering new £80 million building with medical school and clinical trials unit in Spring 2018
- The charity has an Advisory Board (with eminent researchers and scientists from Norwich, London, Oxford and Cambridge) and is actively looking at complimentary and collaborative projects, which will increase the research knowledge base and translate research into treatments.

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.

## Invest in ME Research

- A UK charity facilitating and campaigning for biomedical research
- Founder member and current Chair of European ME Alliance
- Has organised twelve annual CPD-accredited international ME conferences in London
- Has organised seven 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
- Has initiated and funded research projects at UCL leading to UK clinical trial of rituximab
- 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

"...with the other expertise and facilities located at the Norwich Research Park, puts it in a very good position to lead a UK and European Centre of Excellence for biomedical research for M.E. to provide possible prevention and solutions."

- Professor Ian Charles Director of the Quadram Institute



## UK Centre of Excellence for ME

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More information from the following links -

- **Research** <http://www.investinme.org/research>
- **Centre of Excellence for ME** <http://www.investinme.org/centre>
- **Fundraising for IiME Research** <http://www.investinme.org/fund>
- **Conference/Colloquium** <http://www.investinme.eu>
- **CofEforME web site** <http://www.cofeforme.eu>

### FAST TRACKING SOLUTIONS FOR ME



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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