A UK Centre of Excellence for ME

Executive Summary Page for MPs

A summary of the work of UK charity Invest in ME Research and researchers in Norwich Research Park in developing a UK/European Centre of Excellence for Myalgic Encephalomyelitis (ME or ME/CFS 1) by facilitating and initiating world class research.

STATUS UPDATE February 2023

- Invest in ME Research is a UK charity funding and facilitating biomedical research into ME/CFS and has raised well over £2 million for research and support activities
- In May 2022 the UK Secretary of State for Health and Social Care proposed looking at developing high-quality research into ME/CFS and building capacity in this field
- The quickest and most cost-effective way to achieve rapid progress is via further development of the UK/European Centre of Excellence for ME/CFS
- The centre in Norwich Research Park already exists with a solid foundation of researchers, facilities and collaboration and has continually expanded since 2013
- An ongoing research programme, new investment, years of recognition for the disease and plans to build more will facilitate rapid progress in advancing research
- The following already exists with the components already in place
    - Experienced team of world class researchers
    - Established research into ME/CFS based on a strategy of collaboration
    - The only clinical trial for ME/CFS in the UK funded and restarting (post-pandemic) in 2023
    - 5 PhDs already funded and experience gained since 2013
    - A new post doctorate fellowship established with Quadram Institute
    - Collaboration in place with major university/institutes/university hospital/clinical trials unit and with other major European institutes
    - A medical school (where the charity has already funded medical students intercalating with research into ME/CFS in their degree course
    - A Biorepository / tissue bank
    - Objective and innovative outcome measures being developed for ME/CFS
    - Links and funding with major funding organisations already – most recently £500k invested in new facilities to support the clinical trial
    - Already established networks to funders and media
    - A collaboration with a well-established ME/CFS clinic in Norfolk
    - Clinicians working with researchers now also examining long covid patients
    - Other international links to researchers and agencies (e.g. NIH)
    - More funding on its way for new and associated research into ME/CFS

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

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[1] ME/CFS is frequently used in this document to avoid confusion with terminology used elsewhere

Background

- A seriously inadequate standard of medical care for ME/CFS 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/CFS and chronic fatigue has led to unscientific research and improper treatments being offered.
- lack understanding of, and training in, ME/CFS amongst medical professionals presents serious risk of misdiagnosis and missed diagnoses with potentially damaging consequences
- There are sparse specialist services available for ME/CFS patients
- Medical students are taught very little or nothing about ME/CFS from a curriculum which uses flawed or out of date information about ME/CFS
- ME/CFS has been identified as a highlighted area by MRC for many years
- ME/CFS identified as a leading cause of long-term absence from school due to sickness for students and teachers
- ME/CFS is recognised by the Department of Health as a chronic neurological illness yet official treatments/management have been aimed at changing patients' false illness beliefs
- In 2015 The USA Institutes of Medicine (IOM) recognised ME/CFS 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 office of the Chief Medical Officer of England stated that they did not know the prevalence in the UK and admitted to knowing little about the disease
- In May 2022, the Secretary of State for Health and Social Care proposed that the Department's chief scientific adviser look into how to develop high-quality research into ME/CFS and support the research community to build capacity and capability in this field.
- The centre in Norwich Research Park already has a foundation of research, facilities, and collaboration that has been developing since 2013 and will facilitate more rapid progress in advancing research into ME/CFS.
- Using what is already set up avoids duplication, leads to more rapid discovery and development of potential treatments, and saves huge costs of starting from nothing.

Proposed Solution

- A UK/European Centre of Excellence for ME/CFS, with the hub based in East Anglia, within the Norwich Research Park, utilising and based on university, institute and university hospital facilities and resources
- The research arm has been 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/CFS

Service Commissioning

- GP referral, via normal NHS channels
- An academic consultant led service with a clinical/academic specialty for ME/CFS to be developed that links with GPs and researchers
- Treatment of patients to be based on sound scientific evidence
- A hub and spoke model: dissemination of expert knowledge to GPs and ME/CFS (and possibly long covid) 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/CFS
- A clinical/academic specialty for ME/CFS to be developed that can be replicated

Benefits

- Unique opportunity to establish a European hub of scientific and clinical excellence in Norwich Research Park, UK
- 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 for discovery
- 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/CFS 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/CFS and creating up to date educational modules which truly reflect the biological basis of the disease
- Establishment of information centre for ME/CFS which would serve patients, carers, the public, politicians, academic and healthcare organisations and the media with correct and up-to-date information about ME/CFS
- Financially viable – UK Centre of Excellence can start small and grow as further funding becomes available (proven already by the work performed)
- Giving citizens their lives back

Current Status of Centre of Excellence for ME/CFS

Since 2012 we have stated that we need a centre of excellence for ME/CFS – and we have already in place all the functioning components, working together, if still underfunded.

We should use what we have developed already – and what we have in Norwich Research Park (NRP) is already impressive and covers practically all of the components that are required and which would provide the most cost-effective way to move forward in the current situation.

Our suggestion is to build on what has been developed already in NRP where we already have an ongoing research programme, new investment, established years of recognition for the disease and plans to build more.

The following already exists with components already in place

- Experienced team of world class researchers
- Established research into ME/CFS with a strategy for further collaborative research
- 5 PhDs already funded and experience gained since 2013
- New post-doctoral fellowship position established to energise research into ME/CFS
- Inter-departmental collaboration already established
- Collaboration with a major university and other institutes already established
- University hospital already collaborating
- The only clinical trial for ME/CFS in the UK (one of only a few in the world) funded and starting
- A Clinical Trials Unit in place and collaborating with the institute
- A medical school (where the charity has already funded medical students intercalating in their degree course and participate in research and education about ME/CFS)
- A Biorepository / tissue bank
- Objective and innovative outcome measures being developed for ME/CFS in association with other disciplines and companies
- Links and funding with major funding organisations already – most recently £500k invested in new facilities to support the clinical trial
- Already established networks to funders and media
- A collaboration with major ME/CFS clinic with thousands of ME/CFS patients already
- Clinicians working with researchers and now also examining long covid patients
- Funding made available and discussions had with NHS for GP champions for ME/CFS
- Links and collaboration to/with other major European institutes and chairing European ME Research Group which involves researchers and clinicians
- The charity has initiated the concept of a European cross-site PhD studentship for ME/CFS to encourage European collaboration and is funding a student who has been working with Nordic colleagues

- Links to a European ME/CFS patient network
- A young/early career European network established
- Major annual international researchers' colloquium and public conferences organised in London since 2006
- Other international links to researchers and agencies (e.g. NIH) already in place in order to maximize research speed and efficiency
- A five-year plan was developed to form a sustainable strategy of biomedical research involving international collaboration
- Further research into ME/CFS soon to be announced and more funding on its way for new and associated research

We have already seen in the time that we have been proposing and developing the centre in Norwich (since 2012) that

- It has encouraged and supported researchers to develop high quality research into ME/CFS co-produced, from inception to dissemination, with people with lived experience of ME/CFS
- It has proactively fostered increased capacity among the research workforce, by bringing in other research disciplines as required to answer the research gaps in this area
- It continues to discuss whether there are skills gaps to improve capability, and how these might be addressed (mainly by investment)
- It has raised awareness of ME/CFS across the research park, and beyond, and has built trust with patients (often charity lead)
- It has raised public awareness of research into ME/CFS – by public meetings, by the Invest in ME Research international conferences and research colloquiums (these have always focused on bringing together researchers, European charities and patient organisations and people with lived experience of ME/CFS.
- It has overcome stigma by emphasising the science that is being applied by world class researchers and institutes and demonstrating that ME/CFS is a real disease

Using the existing setup that has already been developed will save time and funding and act as the focal point and a catalyst for ideas for further research in a joined up strategy.

> "With over 3000 scientists at the Norwich Research Park, consisting of 4 world leading research institutes, a university and a teaching hospital, it is one of Europe's largest single-site concentrations of research in Food and Health and Environmental sciences.

Having academic excellence across a range of diverse, but related fields, in one location is a very powerful way to deliver a step-change in potential outcomes across a number of health issues.

Importantly, the new centre for food and health, due to open at the end of 2017 at the Norwich Research Park, takes co-location to a new level as it uniquely integrates academic excellence with clinical expertise; by bringing together the Institute of Food Research with aspects of the University of East Anglia's medical school and science faculty with the Norfolk and Norwich University Hospitals' gastrointestinal endoscopy facility, working alongside industry.

The new Institute will provide a novel holistic, systematic and integrated approach to deliver faster innovation as well as helping to inform government policy on a range of gut and diet related issues including M.E.

The development of this new centre, together 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 Quadram Institute Bioscience

Journal of IiME Abstract 2015

The NIH adopted this model and funded four centres that were set up to collaborate in research into ME/CFS. They have now been running for several years and a new tranche of funding has now become available.

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. 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 (with a knock-on effect possibly for long covid).
- The charity continues to support this centre and more research is already planned.

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 funding and support for the final, and vital, elements of the UK Centre of Excellence for ME/CFS and create a future whereby people with ME/CFS may be given back their lives.

Invest in ME Research

- A UK charity funding and facilitating biomedical research into Myalgic Encephalomyelitis (ME or ME/CFS)
- Is a founder member and current Chair of European ME Alliance
- Has been organising annual international CPD-accredited ME research Conferences and research Colloquiums in London since 2006 with thirty major research institutes, organisations and agencies from around the world regularly attending, including NIH and CDC
- Is allied to a UK patient-led campaign called Let’s Do it for ME that crowdfunds for Invest in ME Research
- Has raised well over £2 million for research and support activities for ME/CFS
- Has funded high-quality biomedical research including investigations into links between ME/CFS and gut microbiome at University of East Anglia/Quadram Institute, working with other institutes and university hospital in Norwich Research Park
- Has also initiated and funded research projects at UCL and supported European research
- Holds worldwide contacts with ME/CFS 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/CFS, which will increase the research knowledge base and translate research into treatments.
- Has fully funded **RESTORE-ME**, the only UK clinical trial for ME/CFS (as of 2022) which is about to begin at Quadram Institute in Norwich
- Is funding further research at the Centre – and that is generating additional research funding from other quarters

Recent Announcements and References

1. UK Charity Pledges £625,000 for Research into ME in Norwich Research Park
2. Meet the researchers behind a new trial into ME
3. Event introduces the RESTORE-ME Clinical trial
4. Quadram Institute – ME/CFS Research Target
5. Major investment for faecal microbiota transplant facility in Norwich
6. Parliamentary Debate 2019
7. The Status of Research, Treatment and Perception of ME in UK of ME 2018
8. Centre of Excellence for ME
9. Centre of Excellence for ME
10. International Conferences and Research Colloquiums
11. UK Charity Announces First Fellowship for Research into ME/CFS in NRP