

A UK Centre of Excellence for ME

Centre of Excellence

It is already here



From UK charity Invest in ME Research's Input to DHSC/UKCRC
ME Research Working Group

A UK Centre of Excellence for ME – An Existing Facility

Invest in ME Research is a UK charity committed to advancing the understanding and treatment of myalgic encephalomyelitis (ME or ME/CFS). The charity has been actively advocating and working towards the establishment of a Centre of Excellence for ME since 2011, situated within the promising grounds of Norwich Research Park.

In August 2022, we submitted a proposal to the DHSC/UKCRC Research Working Group, outlining what we believe is the most efficient, cost-effective, and forward-thinking approach to enhancing our knowledge of the aetiology of ME and developing treatments. This proposal represents a significant step toward building capacity and expertise in the field.

This document contains the relevant extract taken from that document.

Given the current limitations on adding agenda items to APPG for ME meetings, we believe it is essential to draw your attention to our proposal independently. We believe the establishment of a Centre of Excellence for ME at Norwich Research Park aligns perfectly with the APPG's mission to facilitate change in the ME landscape.

For more detailed information and insight into our proposal, we encourage you to review the accompanying document, '*Executive Summary for MPs*' regarding the Centre of Excellence for ME development, which can be accessed at this link - <https://tinyurl.com/UK-Centre-of-Excellence-for-ME> .

For additional inquiries or to discuss this proposal in more detail, please feel free to reach out to us directly,

Kathleen McCall

Chairman Invest in ME Research

UK Registered Charity Nr. 1114035

PO BOX 561,
Eastleigh SO50 0GQ
UK

www.investinme.org

email: info@investinme.org



[This document is available at <https://tinyurl.com/appg-for-me-november2023>]

Our View on a Different Approach

With an initiative such as this DHSC/UKCRC Research Working Group for ME/CFS¹ there seems to be a tendency to create a wish list of many different requirements being put up and yet without a realistic plan to achieve in the current environment that is adequately backed by financial support – i.e. funding to make it happen.

Yet there is one area that we have not seen in the documents supplied by the UKCRC – i.e. what we already have in place.

In the context in which we find ourselves (little capacity, little or no funding) then the quickest way to build and develop is to avoid reinvention and use what we have already – what has been funded or developed and holds potential for developing more rapidly than spending two years writing documents.

Norwich Centre of Excellence

Since 2012 the charity has stated that we need a centre of excellence for ME – and since that time we have already in place all of 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 to avoid calling for huge investment from day 1.

Our suggestion is to utilise what exists at 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
- 5 PhDs funded
- The first fellowship for ME established and funded

¹ The charity prefers the acronym ME for myalgic encephalomyelitis. ME/CFS is frequently used in this document to avoid confusion with terminology used by UKCRC

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- Inter-departmental collaboration already established
- Collaboration with major university and other institutes already established
- University hospital already collaborating
- The only UK clinical trial for ME funded and starting – one of only a few in the world
- A Clinical Trials Unit in place and collaborating with the institute
- Medical school (where the charity has already funded medical students intercalating in their degree course and participate in research and education about ME)
- Biorepository / tissue bank
- Objective and innovative outcome measures being developed in association with other disciplines and companies
- Links and funding with major funding organisations already – most recently £500k invested in facilities to support the clinical trial
- Already established networks to funders and media
- Collaboration with long established ME clinic with thousands of ME patients already
- Clinicians working with researchers and now also examining long covid patients
- GP champions for ME with NHS
- Links and collaboration to/with other major European institutes and chairing European ME Research Group which involves researchers and clinicians
- Links to European ME Alliance patient network
- Major annual international researchers' colloquium organised for twelve years
- Other international links to researchers and agencies (e.g. NIH) already in place
- Further research into ME 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

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- 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 across the research park, and beyond, and has built trust with patients (often charity lead)
- It has raised awareness of research into ME – 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.
- It has overcome stigma by emphasising the science that is being applied by world class researchers and institutes and demonstrating that ME is a real disease

Using the existing setup will save time and funding and be the focal point for ideas for further research in a joined up strategy.

The NIH took this idea and funded four centres that would collaborate. They have now been running for several years and a new tranche of funding has now become available.

We should use what we have created already as a base and model.

So our proposal is –

- Use what has already been developed in Norwich Research Park and expand and augment the centre there with additional funding to act as a focal point for research into ME, which will then be useable as a way to achieve all of the other objectives.
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“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 centre for food and health, ...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 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 ME.

The development of this 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**

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Further Information

1. *'UK Centre of Excellence for ME – Executive Summary for MPs'* –
<https://tinyurl.com/UK-Centre-of-Excellence-for-ME>
2. ME/CFS Research at Quadram Institute, Norwich
<https://quadram.ac.uk/targets/me-cfs/>