

Invest in ME Research Press Release July 2020

UK Charity Agrees Major Funding Award for Research into Myalgic Encephalomyelitis in Norwich Research Park

For Immediate Release

28th July 2020

UK Charity Invest in ME Research is awarding £625,000 for continued research into the disease myalgic encephalomyelitis (ME or ME/CFS) in Norwich Research Park, UK.

This major investment is an increase in the charity's previous pledge of £500,000 that was announced in late 2019.

This research builds on the foundations already made for a UK/European Centre of Excellence for ME research hub in Norwich Research Park.

The new pledge will cover the required funding for a clinical trial of Faecal Microbiota Transplantation (FMT) that will be performed alongside other high-quality biomedical research at the Quadram Institute (QI).

QI's world-class facility has already seen five PhDs employed on research into ME, focusing specifically on the gut microbiome and links to ME.

The charity has committed to the award of £45,000 to co-fund the latest PhD studentship with the University of East Anglia.

Invest in ME Research Chairman Kathleen McCall said:

"The charity and its dedicated supporters have continued to develop a strategy of high-quality biomedical research in partnership with world-class institutes at one of the most outstanding research parks in Europe.

We are a small charity but are determined to follow a pathway for biomedical research into this disease with the emphasis on the urgency that it requires.

Our further commitments again demonstrate our confidence in the quality and direction of research at Quadram Institute.

This new award has been facilitated by the support and generosity of The Hendrie Foundation who have pledged support for the charity and follows support from the foundation for previous charity-funded research into ME.

People with ME will be enormously grateful to the Hendrie Foundation for their continuing support for this neglected disease.

Developing a major clinical trial for ME that offers a new form of treatment for ME using modern facilities and developing solid outcome measures brings hope to all people who have ME, and their families.

With the existing funded research, the support and facilitation of new initiatives with the European ME Research Group (EMERG) and working with our colleagues in the European ME Alliance (EMEA), then the charity continues to assist in changing the face of research into this serious and debilitating disease."

Professor Simon Carding, Head of Gut Microbes and Health Research Programme at Quadram Institute Bioscience said:

"We are incredibly grateful for the ongoing support from Invest in ME Research and their supporters. We are very excited at the prospect of undertaking the FMT clinical trial, as part of our ongoing investigations into the links between ME and the gut microbiome."

The continuing and developing research in Norwich Research Park holds out great hope for the future for ME patients and their families.

ME commonly presents with hugely diverse and debilitating symptoms including post-exertional malaise, unrefreshing sleep, cognitive dysfunction and widespread pain. It has been estimated that ME affects around 250,000 people in the UK and direct and indirect economic costs have been estimated in the USA to be \$20 billion annually. The severity of symptoms varies. Around 25% of sufferers may be classed as severely affected - often bed bound at some point in their lives with periods of relapse and remission common and only 6% returning to full health.

These awards bring to five the number of PhD positions that the charity has funded/part-funded for research into ME.

ENDS

Notes for editors

About Invest in ME Research

Invest in ME Research (charity nr 1153730) is an independent UK charity finding, funding and facilitating biomedical research into ME.

Invest in ME Research is run by volunteers - patients or parents of children with ME - with no paid staff. Overheads are kept to a minimum to enable all funds raised to go to promoting education about ME and facilitating and funding biomedical research into ME. The charity organises an annual International ME

Conference Week in London that includes a two-day research Colloquium, a Young/Early Career Researcher conference, a Clinicians Workshop and a public International conference that regularly has delegates from twenty countries attending.

The charity's efforts are on developing the Centre of Excellence for ME to maintain a strategy of high-quality biomedical research into the disease and encouraging European collaboration in research and development of clinical expertise.

For more information visit www.investinme.org/news

Contact details [Chairman Kathleen McCall, Invest in ME Research, PO BOX 561, Eastleigh SO50 0GQ, UK email: info@investinme.org]

About the Quadram Institute

The Quadram Institute (quadram.ac.uk) is an interdisciplinary research centre at the forefront of a new era of food and health research. It brings together researchers and clinicians under one roof and houses one of Europe's largest endoscopy units and a clinical research facility.

Based on the Norwich Research Park, The Quadram Institute is a partnership between Quadram Institute Bioscience, the Norfolk and Norwich University Hospitals NHS Foundation Trust, the University of East Anglia and the Biotechnology and Biological Sciences Research Council (BBSRC). Its mission is to deliver healthier lives through innovation in gut health, microbiology and food and its vision is to understand how food and microbes interact to promote health and prevent disease.

Four interconnected research themes in Quadram Institute Bioscience deliver a pipeline of research in plants, microbes, food and health: microbes in the food chain; the gut and the microbiome; food innovation and population health.

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About University of East Anglia

The University of East Anglia (UEA) is a UK Top 25 university and is ranked in the top 50 globally for research citations. Known for its world-leading research and good student experience, it was awarded Gold in the Teaching Excellence Framework and is a leading member of Norwich Research Park, one of Europe's biggest concentrations of researchers in the fields of environment, health and plant science. www.uea.ac.uk

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