ME: VITAL NEW RESEARCH COULD LAY BARE CAUSE OF 'WORLD’S CRUELLEST ILLNESS'

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THE ME ASSOCIATION ANNOUNCES THREE RESEARCH GRANTS INTO INCURABLE DISEASE THAT AFFECTS 250,000 BRITS

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Vital research funding that could lay bare the cause of one of the world’s cruellest illnesses can today be announced by the ME Association.

The UK charity is proud to reveal it is funding three new projects to help solve the mysteries of myalgic encephalomyelitis - also known as chronic fatigue syndrome - and how it is treated.

Manifesting as unrelenting exhaustion, profound pain, memory difficulties and worsened mobility, ME/CFS is destroying the lives of 250,000 people in the UK, including children and teenagers.

One in four are so severely affected that they are rendered housebound or bedbound - with some even reliant on tube feeding. Sufferers are often confined to their beds, unable to walk, and need help even to shower - an action that could then lay them low for hours, or even days.

There is no known cure - and worse still, there remain vast misconceptions and ignorance surrounding the illness - even in medical circles.

Today, campaigning charity The ME Association can announce a new tranche of funding totalling almost £200,000 through its Ramsay Research Fund.

The charity - which relies solely on donations and membership fees - has already invested more than a million pounds in biomedical research. It considers quality research to be a key priority as it offers the best hope for better understanding, improved diagnosis and treatment.

Medical adviser, Dr Charles Shepherd, said: “The ME Association is delighted to announce that our Ramsay Research Fund has been able to make three major research grants totalling nearly £200,000.

“All three projects constitute major steps forward in helping to understand the underlying cause of ME, the search for a diagnostic biomarker, and the provision of more effective management - especially during the crucial early stages of this illness.

“Thanks must go to our many loyal supporters and fundraisers who have been raising money for medical research into the cause and treatment of ME.”

Grant one: The ME Biobank (£99,766)

The world-leading ME/CFS biobank is the only one of its kind in the UK.

Here, the analysis of blood samples stored at the biobank could reveal crucial biomarkers to provide a deeper understanding on what causes ME, and how it could be accurately diagnosed and treated.

The project, led and managed by the Biobank team at the London School of Hygiene & Tropical Medicine, is funded through the ME Association’s Ramsay Research Fund.

This new ME Association funding will sustain and allow the Biobank to expand over the next two years and ensure a steady supply of blood samples to ME researchers around the world.

Jack Butterworth, a Project Manager at the UK ME/CFS Biobank (UKMEB), said: “Over the past two years we have released samples to six research institutions in the UK alone, and many more in Europe, South America, Asia and the USA.

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“The new, two-year award will build on that success, enabling further releases and the replenishment of depleted samples.

“The award will also enable further communications and fundraising projects, raising the Biobank’s income and reducing its reliance on grant funding.

“The funding will also allow the team to continue to work to develop biobanks elsewhere in the world, using protocols that are harmonised with the UKMEB’s. Exciting work is already underway in the USA, Canada and Australia.

“The UKMEB continues to be an example to biobanks in ME/CFS and in other fields, and has published its work in peer-reviewed journals and presented at major conferences.”

- More information on the work of the UKMEB can be found at https://cureme.lshtm.ac.uk/

Grant two: Dr Karl Morten and the University of Oxford (£69,150)

The ME Association is delighted to announce it has granted vital funding to Dr Karl Morten and colleagues at the University of Oxford, who are investigating blood abnormalities in ME patients.

The funding will enable scientists to continue examining a link between blood plasma abnormalities and dysfunctional mitochondrial energy production in ME patients.

This grant will also help to bring in more Oxford researchers from various disciplines and create a Centre of Excellence for ME Research in Oxford.

Dr Morten said: “We are extremely grateful to the ME Association for providing funding for our new 12-month project exploring the plasma factors in ME/CFS and their impact on mitochondrial function.

“This study will compare ME/CFS patients with patients diagnosed with other fatigue-inducing conditions to look at changes in mitochondrial dynamics.”

Grant three: Dr Keith Geraghty and the University of Manchester (£25,000)

The third grant goes to Dr Keith Geraghty and colleagues at the University of Manchester, where it will be used to analyse what happens to ME patients in the crucial time between onset of their ME symptoms and a diagnosis being made.

It is the first time research in this area has been commissioned on such a level.

Dr Shepherd said: “This is key part of the patient journey where we know that there are serious problems in both obtaining an early and accurate diagnosis, and then being given appropriate advice on management.”

The results will also be fed into the development of the new NICE (National Institute for Health and Care Excellence) guidelines on the diagnosis and management of ME/CFS.

Dr Geraghty said: “ME is a disabling condition that greatly impacts the lives of sufferers. Many sufferers report problems getting an early diagnosis and appropriate medical care.

“We found almost no research on the ‘diagnosis of ME/CFS’, specifically how long it takes patients to get a diagnosis in the UK and the process patients go through to get a diagnosis.

“We want to explore this topic to better inform clinical practice and guidelines for treatment.”

Why ME Association funding is vital - and how you can help

Less than £1 is spent each year per person suffering from ME by the Government and there is a chronic lack of funding for medical research.

Many doctors still don’t know how to diagnose or manage the condition.

A parliamentary debate last year was told how people with ME are more than six times likely to commit suicide.

Research grants are made by the ME Association from funds generated by donations and fundraising drives.

Please help us to continue with our vital work.

Donations can be made here:
https://www.justgiving.com/campaigns/charity/meassociation/ramsayresearchfund

Visit the ME Association website for more information: https://www.meassociation.org.uk

NOTES:

Press Enquiries: John Siddle - 07598032845 / john.siddle@meassociation.org.uk

Company Contact:

ME Association

E. meassociationpress@gmail.com
W. https://www.meassociation.org.uk

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