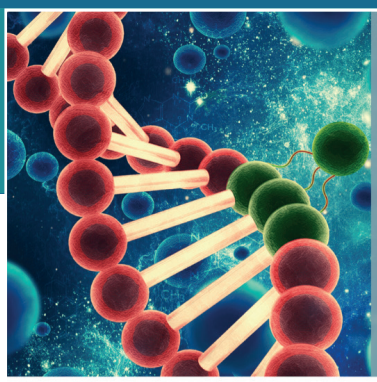
PATIENTS, SCIENTISTS, AND ADVOCATES CELEBRATE

£3.2m Funding for DecodeME, the Largest Ever Genetics Study!



"This project is very significant in its scale and ambitions. It signals the shared commitment of funders, researchers and patients to work together to gain new insights into ME/CFS."

Prof Fiona Watt, Executive Chair, Medical Research Council, which is helping to fund DecodeME

Decode ME
The ME/CFS DNA Study

Register to take part at www.decodeME.org.uk

DecodeME Press Release

23 June, 2020

Funding for the world's largest genetic study into myalgic encephalomyelitis (M.E.), led by a partnership of patients and scientists, was announced on 23rd June.

Despite its high cost to patients, the economy, the NHS and society, very little is known about the causes of M.E., also diagnosed as chronic fatigue syndrome (CFS, or ME/CFS), including how to treat it effectively.

Now, thanks to £3.2 million funding, awarded jointly by the Medical Research Council and National Institute for Health Research, work can begin on DecodeME, the ME/CFS DNA study that hopes to reveal the tiny differences in a person's DNA that may affect their risk of developing ME/CFS, and the underlying causes of the condition.

DecodeME will look at samples from 20,000 people with ME/CFS, in the hope that the knowledge discovered will aid development of diagnostic tests and targeted treatments.

ME/CFS affects an estimated 250,000 people in the UK, of all ages, and from all social and economic backgrounds.

Post-exertional malaise, an adverse reaction to levels of exertion that many might consider trivial, is often considered to be the defining symptom – this can leave patients suffering from symptoms including extreme levels of fatigue, pain, inability to process information, and light and noise sensitivities.

One in four people with ME/CFS are so severely affected they are house- and frequently bed-bound.

"Having been involved in the planning and development of the DecodeME study we are delighted to learn that the Medical Research Council and the National Institute for Health Research have agreed to provide a massive grant of over £3 million to ensure that this research can now commence.

"This type of 'genetic fingerprint' study is already providing important information about the cause of some types of eye disease, Parkinson's disease and prostate cancer.

"Finding the genetic fingerprints for ME/CFS could therefore provide us with vital clues to help with diagnosis, treatment and even the prevention of ME/CFS.

"Active patient involvement is right at the centre of the Decode ME study and the CURE ME team at M.E. Biobank, which is funded by the ME Association Ramsay Research Fund, will be playing a central role in patient recruitment.

"So we hope that people will now sign up and register their willingness to take part in this exciting new biomedical research project."

Dr Charles Shepherd
Hon. Medical Adviser, ME Association.

DecodeME, the world's largest ME/CFS DNA study NEEDS YOU!

Register now at www.decodeME.org.uk

PATIENTS, SCIENTISTS, AND ADVOCATES CELEBRATE

£3.2m Funding for DecodeME, the Largest Ever ME/CFS DNA study!

"It is our hope that this study will transform ME/CFS research by injecting much-needed robust evidence into the field."

Register at www.decodeME.org.uk

DecodeME's Principal Investigator
Prof Chris Ponting, MRC Human Genetics Unit, University of Edinburgh

DecodeME
The ME/CFS DNA Study

DecodeME Press Release

23 June, 2020

Andy Devereux-Cooke, one of the patients leading DecodeME:

"As someone living with ME/CFS, I'm well aware that the patient community has waited a long time for a study such as this one that has such a strong, genuine element of patient involvement.

"All of us involved with this research project hope that it can start to address the totally unwarranted stigma and lack of understanding that so many patients with ME/CFS face on a daily basis."

Principal Investigator Prof Chris Ponting, MRC Human Genetics Unit, University of Edinburgh:

Partnering with the MRC Human Genetics Unit at the University of Edinburgh and the London School of Hygiene and Tropical Medicine, it is being led by the ME/CFS Biomedical Partnership.

"Our focus will be on DNA differences that increase a person's risk of becoming ill with ME/CFS. We chose to study DNA because significant differences between people with, and without, ME/CFS must reflect a biological cause of the illness.

"It is our hope that this study will transform ME/CFS research by injecting much-needed robust evidence into the field."

Sonya Chowdhury, Chief Executive, Action for M.E., and Chair of the study Management Group:

People with ME/CFS across the UK will be asked to volunteer to take part in DecodeME, which they can do from home, confirming they meet the selection criteria via a patient questionnaire already being used by the CureME Biobank. Participants will be mailed a collection kit and asked to send back a saliva or "spit-and-post" sample. These will be compared with samples from healthy controls.

"Simply put, we cannot do this without the determination and support of people with ME/CFS.

"Recruiting the 20,000 people we need is challenging – but absolutely achievable, by working in partnership with the CureME Biobank, charities, patient advocates, local support groups and others."

Co-Principal Investigator Dr Luis Nacul, CureME Biobank, London School of Hygiene and Tropical Medicine:

"Unlocking the genetic susceptibility to ME/CFS is a key part of understanding what causes ME/CFS and the disease mechanisms involved.

"This, in conjunction with other biomedical research into ME/CFS, should finally pave the way to better diagnosis and the development of specific treatments for this debilitating disease."

Professor Fiona Watt, Executive Chair of the Medical Research Council, which is helping to fund DecodeME:
"This project is very significant in its scale and ambitions.

"It is one of the biggest studies into potential genetic connections to ME/CFS and I would like to congratulate Prof Chris Ponting and his colleagues on this award.

"It signals the shared commitment of funders, researchers and patients to work together to gain new insights into ME/CFS."

Dr Louise Wood, joint head of the National Institute for Health Research:

"Patient involvement – one of NIHR's key values – has been embedded throughout, bringing huge relevance and value to the project."

The study is scheduled to begin in September, with recruitment of participants from March 2021. Anyone with ME/CFS aged 16 years or over who wants to take part in the DecodeME study can register their interest now by visiting: www.decodeme.org.uk