- Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)

Chronic fatigue in the genes

People with chronic fatigue syndrome have distinct genetic differences to those who don't have the condition, new research finds.

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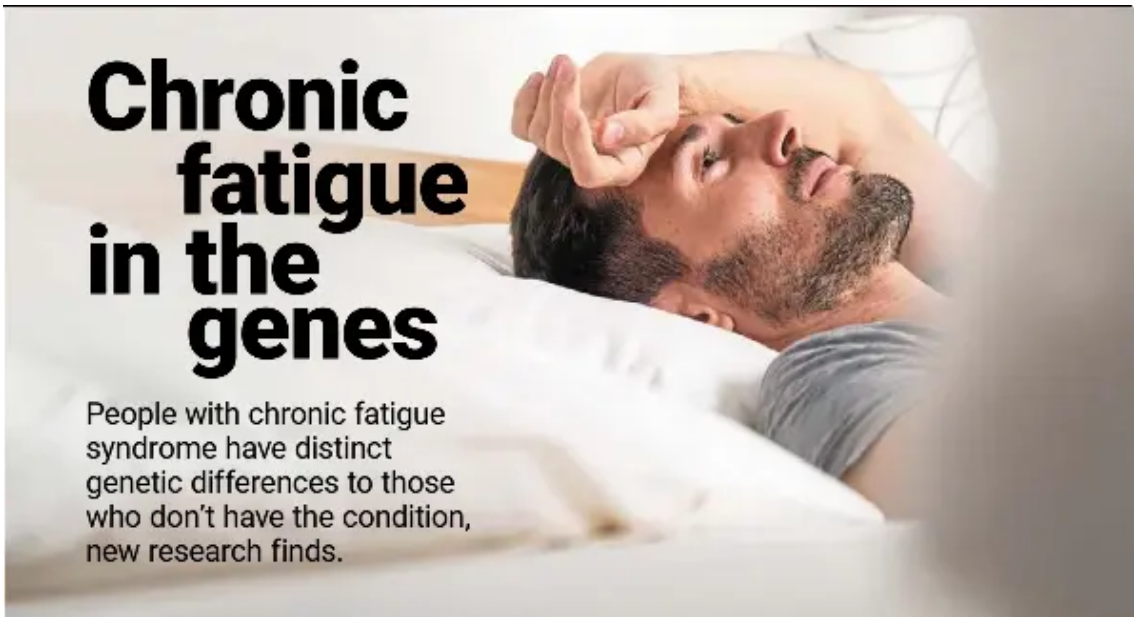
PEOPLE diagnosed with myalgic encephalomyelitis (Me)/chronic fatigue syndrome (CFS) have significant differences in their DNA (deoxyribonucleic acid), compared to those without the condition, according to a "groundbreaking" new study in Britain.



The scientists involved said the findings offer the first robust evidence that genes contribute to a person's chance of developing the disease.

The Decodeme study, said to be the largest of its kind in the world, uncovered eight areas of genetic code in people with ME/ CFS that are markedly different to the DNA of people without the condition.

They hope that the findings will boost "validity and credibility" for affected patients, and help rebuff some of the stigma and lack of belief that exists around the condition.

There is currently no diagnostic test or cure for ME/CFS, which is believed to affect around 67 million people worldwide.

Very little is known about what causes it.

A key feature of the condition is a disproportionate worsening of symptoms following even minor physical or mental activity, known as post-exertional malaise (PEM).

Other symptoms include pain, brain fog and extreme energy limitations that do not improve with rest.

Related to infections

For the new study, the researchers analysed 15,579 DNA samples from the 27,000 people with ME/CFS participating in Decodeme, described as the world's largest dataset of people with the disease.

The eight regions of DNA where scientists found genetic differences involve genes linked to the immune and nervous systems.

At least two of the genetic signals relate to how the body responds to infection, which researchers said aligns with long-standing patient reports that the onset of symptoms often followed an infectious illness.

Decodeme investigator and University of Edinburgh Medical Bioinformatics Chair Prof Dr Chris Ponting said: “This is a wake-up call.

“These extraordinary DNA results speak the language of ME/CFS, often recounting people’s ME/CFS symptoms.

“Decodeme’s eight genetic signals reveal much about why infection triggers ME/CFS and why pain is a common symptom.

“ME/CFS is a serious illness and we now know that someone’s genetics can tip the balance on whether they are diagnosed with it.”

As a person’s DNA does not change over time, experts say the genetic signals identified would not have developed because of ME/CFS and are therefore likely to reflect the causes of the disease.

Populations used in the initial study were limited to those from European ancestries.

Decodeme research studying DNA data from all ancestries is ongoing.

ME/CFS affects more females than males, although researchers found nothing to explain why this is the case.

The Decodeme team is now calling on researchers from around the world to access its “rich” dataset and help drive forward targeted studies into

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ME/CFS.

Breaking down disbelief

Decodeme co-investigator and British charity Action for ME chief executive Sonya Chowdhury said: “These results are groundbreaking.

“With Decodeme, we have gone from knowing next to nothing about the causes of ME/ CFS, to giving researchers clear targets.”

She also hopes the discoveries will help change the way the condition is viewed.

She said: “This really adds validity and credibility for people with ME.

“We know that many people have experienced comments like ‘ME is not real’, or they’ve been to doctors and been disbelieved or told that it’s not a real illness.

“Whilst things have changed and continue to change, that is still the case for some people and we hear that repeatedly as a charity.

“Being able to take this study into the treatment room and say there are genetic causes that play a part in ME is going to be really significant for individuals.

“It will rebuff that lack of belief and the stigma that exists.”

The findings have been reported in a pre-print publication, or unpublished study.

During a media briefing about the study, researchers were asked about similarities between the symptoms of long Covid and ME/CFS.

Prof Ponting said: “It’s very clear that the symptomology between long Covid and ME is highly similar.
“Not for everyone, but there are substantial similarities.
“But as a geneticist, the key question for me is: are there overlapping genetic factors?
“And we haven’t found that in Decode ME with the methods that we’ve employed.
“One of the key things that we’re doing is enabling others to use their different approaches to ask and answer the same question.”
Decodeme is a collaboration between the University of Edinburgh, Action for ME, the Forward ME alliance of charities, and people with ME/CFS.
It is funded by the UK Medical Research Council and UK National Institute for Health and Care Research. – PA Media/dpa