

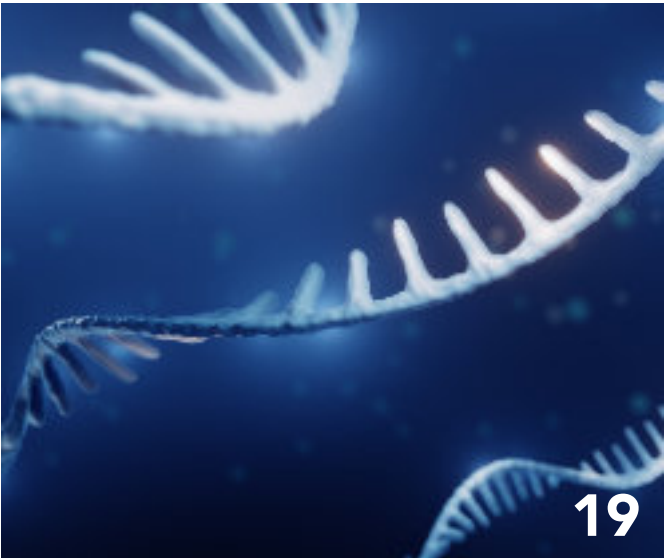
NEWS OF THE ME RESEARCH YOU ARE HELPING TO FUND

# breakthrough



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*Breakthrough* magazine is published by ME Research UK, a Scottish Charitable Incorporated Organisation with the principal aim of commissioning and funding high-quality scientific (biomedical) investigation into the causes, consequences and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We influence, inform and invest in ME research globally by identifying potentially important areas for future biomedical research, and by producing high quality professional reviews and reports. *Breakthrough* is an open-access publication and, apart from images and illustrations, the content may be reproduced free of charge, subject to the terms and conditions found at [meres.uk/bt-terms](https://meres.uk/bt-terms).

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# In the spotlight

What's happening in the world of ME research and funding

## Editorial

Welcome to our Spring 2023 issue of *Breakthrough* magazine.

In September 2021, we were delighted to reach something of a milestone, having funded £2.1 million of research in our 21 years as a charity. Just eighteen months later, we have now surpassed £3 million in research funding, and have both the capacity and drive to keep this rate of progress going.

Of course everything we do is only possible as a result of your support, and we are indebted for it. This issue, in particular, highlights some wonderful examples of the fundraising activities undertaken to ultimately provide us with the means to continue our work on your behalf. We have also included a leaflet with this issue explaining more about how you can leave ME Research UK a gift in your Will, if that is something you are able to consider.

Alongside our continued funding of established researchers (with a summary of the latest results from Jo Nijs's research in this issue), this year has seen our third PhD research grant award (in Australia) with a fourth in the pipeline – a demonstration of

our continued focus on encouraging bright young researchers into the field.

The major DHSC initiative started by Sajid Javid in May last year is progressing, and we remain actively engaged in the development of a research strategy to inform a cross government delivery plan for ME. We have no doubt that many challenges lie ahead, but alongside the recent parliamentary debate held in the Scottish Parliament, we remain cautiously optimistic that the landscape is changing for the better. Cort Johnson's latest 'postcard from Nevada' in this issue really highlights both the opportunities and challenges the ME research community faces.

Thank you for your continued support, and I hope you enjoy this issue of *Breakthrough*.

Jonathan Davies  
Chair, Board of Trustees

## Facebook

One of the best ways you can quickly and easily raise funds for ME Research UK is via a birthday fundraiser on Facebook (see [bit.ly/36d6o3h](https://bit.ly/36d6o3h) for guidance).

It's a great way to ask friends and family to help celebrate your birthday by donating to a cause that's close to you, while at the same time raising awareness of ME/CFS.

The best bit? There are no fees for donations made to charities on Facebook, so all the money goes direct to the cause you are supporting.



## Walk for ME

Team Walk for ME 2023 has now been launched. Every year, this amazing scheme encourages supporters to walk, run, swim and ride to raise money for research into ME.

ME Research UK is grateful once more to be chosen as one of the two featured charities.

Since it started in 2013, Walk for ME has raised well over £200,000 for charity. Wherever you are, we hope you will become involved this year.

You choose when and how far to walk, and the charity to support. You will be supporting a great cause and raising awareness with every stride.

[meres.uk/wfME2023](https://meres.uk/wfME2023)



## Scotland's forgotten illness

### *Parliamentary debate on ME/CFS*

On 2 February, in response to a Motion put by Sue Webber MSP, the Scottish Parliament held a debate on ME/CFS, its symptoms, and the findings of the Scottish stakeholder review of the ME/CFS NICE guideline.

Opening the debate, Sue Webber described ME/CFS as “Scotland’s forgotten illness” and gave personal testimonies from her constituents, illustrating the realities of living with the disease, and the lack of empathy and knowledge sometimes shown by healthcare professionals.

Sixty-one MSPs had signed the Motion, and many also highlighted the real-life experiences of constituents with ME/CFS who had contacted them.

Donald Cameron MSP summarised the issues raised by these people, that: ME/CFS is a legit-

imate and debilitating illness, but is not yet understood fully; there is a lack of access to services; and more investment is needed to find a cure. He urged that this debate is the “start of a change” in Scotland.

Jackie Baillie MSP gave useful background to the situation in Scotland. There is no specialist ME/CFS consultant and only one specialist nurse. Despite the disease’s estimated cost to the Scottish economy of £360 million, the Scottish government has funded only two ME/CFS-related projects in the last decade.

On behalf of the Scottish Government, Maree Todd (Minister for Public Health, Women’s Health and Sport) stated that, “It is clear from the voices that we have heard this afternoon that many people with ME/CFS have



felt stigmatised or disbelieved by those who do not understand their condition. Therefore, the first thing that I have to say is that I want that stigma and disbelief to end. We have made a visible commitment to supporting the recent changes to the ME/CFS guidance, and we continue to work to raise awareness of the condition and the impact on those who live with it.”

ME Research UK was invited to submit a research briefing to go to MSPs ahead of the debate, which joined those on a number of ME/CFS topics prepared by other charities. The box on the right summarises some of the points we raised.

However, on the subject of research, apart from mentioning the Delivery Plan’s aspects looking at ways to improve the number and quality of research applications, the Minister was disappointingly silent.

## Key research challenges

- Biomedical research has identified a range of biological abnormalities in people living with ME/CFS, covering diverse fields such as immunology, genetics, muscle biology, pain medicine and the cardiovascular system.
- The exact biological mechanisms driving the disease remain only partially explained.
- Many clinicians remain unaware of this research and still regard ME/CFS with scepticism.
- There is little agreement on the appropriateness of the illness name: ME, CFS, ME/CFS or other terms in use.
- The lack of consensus on diagnostic criteria can make it difficult to compare the findings of different studies.
- There are not yet any validated biomedical biomarkers to aid in the diagnosis and acceptance of the illness.
- The Medical Research Council (MRC) recognises the need for better diagnosis and treatments, and has made ME/CFS a high-priority research area. But they have allocated only a small amount of funding to ME/CFS, and many scientists find it difficult to secure support.
- In 2022, the UK Government emphasised the ten priority research questions that need to be addressed, and set out a cross-Government delivery plan for England, aligned with plans in the Scottish Government, to drive high-quality research into ME/CFS and support the research community to build capacity and capability in this field.
- The MRC recently awarded funding for DecodeME, the world’s largest genome-wide association study of ME/CFS, which aims to aid the development of diagnostic tests and targeted treatments.
- Despite this welcomed funding, ME/CFS remains a seriously underfunded disease, particularly when compared with cancer, diabetes, cardiovascular disease and multiple sclerosis.



## ME Research UK reaches new milestone

### *More than £3 million invested in ME/CFS research*

Around the beginning of this year, the total amount of money ME Research UK has invested in ME/CFS research during the charity's lifetime exceeded the £3 million mark.

This is a significant milestone for us as the UK's largest non-government funder of research into this disease, and one we could not have achieved without the generosity and hard work of our many supporters and fundraisers.

Since the establishment of ME Research UK in 2000, the charity has relied on this fundraising to provide financial backing to more than sixty research projects to date over our 23-year history.

We only fund projects which are based on sound science and which have been peer-reviewed and assessed by our Science Committee. And we only fund projects when we have money in the bank to pay for the research

to which we have committed.

This money comes from a variety of sources, including direct donations and the marvelous efforts of our fundraisers. But one important source is legacies.

This issue of *Breakthrough* is accompanied by a leaflet explaining more about how you can leave ME Research UK a gift in your Will, if that is something you are able to do.

But it is also a good opportunity to highlight a number of re-

*“We could not have achieved this milestone without our supporters’ generosity”*

## AmazonSmile

We would like to say a huge thank you to everyone who has used AmazonSmile and selected ME Research as their chosen charity.

We received more than £1,900 from this scheme over the last three months thanks to supporters. However, AmazonSmile sadly closed in February.

However, there are still other online, free-to-use fundraising sites such as Easyfundraising, Give with Bing, and Give as you Live.

Find out more here:  
[meres.uk/shopping](https://meres.uk/shopping)

cently funded projects all made possible thanks to a legacy from the Fred and Joan Davies Bequest.

To date, this bequest has enabled surgeon Mr James Allison to explore the role of the autonomic nervous system in the painful symptoms experienced by people with ME/CFS; Dr Leighton Barnden to investigate abnormalities in the brain stem using new imaging technologies; and Dr Sarah Annesley to look more closely at changes in mitochondrial energy production.

What’s more, there are at least

three more new studies that we are planning to announce this year thanks to this Bequest.

Of course, this is not the only way people can help support our work, and we are so grateful to everyone raising funds in other ways such as sponsored and other events, some of which you can read about on page 20.

ME Research UK remains committed to our mission to inform, influence and invest in ME research, and to make a real difference to the lives of people with ME/CFS, which we can continue to do with your help.



# Cause and effect

A new PhD project in Australia looks at **mitochondrial abnormalities in ME/CFS** in more detail

**W**e were very pleased to announce this year a new award for PhD-level research. This project is being conducted at La Trobe University in Melbourne, Australia by PhD student Tina Katsaros supervised by Dr Sarah Annesley.

Dr Annesley's research is focused on the mitochondria, the so-called power plants of the body. These structures are found

in every cell in the body, and their role is to convert energy from our food into a form our cells can use, namely molecules called ATP (adenosine triphosphate).

## The mitochondria

It is therefore no surprise that a significant amount of research into ME/CFS has looked at whether there are abnormalities in the mitochondria and their production of ATP, since this

'energy currency' is crucial to normal functioning of the body.

Much of the research evidence suggests that the mitochondria are indeed dysfunctional in ME/CFS, including previous work from Dr Annesley in which her group identified two specific abnormalities in the final stage of ATP production in the mitochondria.

In white blood cells called lymphoblasts they found that: (1) an enzyme called ATP synthase



**Tina Katsaros**



**Dr Sarah Annesley**

produced ATP less efficiently in ME/CFS cells than in control cells, and (2) the activity of an enzyme complex called TORC1 (which regulates this process) was increased in ME/CFS cells.

ME Research UK is currently supporting Dr Annesley to investigate this further in other types of cells called fibroblasts, while Tina's new PhD project aims to investigate the mitochondrial abnormalities in more detail, and specifically how they interact.

Tina plans to use a battery of different tests on lymphoblastoid cells from people with ME/CFS and healthy controls, as well as from other patients with genetic mutations known to affect the function of ATP synthase and

TORC1. The tests include measurements of mitochondrial respiration, mitochondrial function and TORC1 activity, as well as some genetic and proteomic assessments.

The main questions the team hopes to answer are whether the previously identified ATP synthase abnormality and/or elevated TORC1 activity cause other cellular abnormalities seen in ME/CFS.

### **Potential treatments?**

The hope is that their findings will help us understand more about how the mitochondria are affected in people with ME/CFS, and help identify which proteins and processes could be targeted by potential treatments.

Tina completed her honours degree under the supervision of Dr Annesley, studying calcium signalling in Parkinson's disease. She developed an interest in the ME/CFS research also being conducted in the laboratory, and now has a desire to make a tangible impact in a field affecting so many people.

Leveraging her own passion and expertise, and that of the Annesley laboratory, Tina starts her PhD project with hopes to better understand the cause-effect relationships between energy pathway abnormalities in cells from people with ME/CFS.

ME Research UK is delighted to be able to support Tina's first research into ME/CFS at this early stage in her career.

# Jo's genes

Are **epigenetic alterations** responsible for pain in ME/CFS and fibromyalgia?

**L**ast year, Prof. Jo Nijs and colleagues at Vrije Universiteit Brussel in Belgium published more results from their ME Research UK-funded study looking at the impact of epigenetics on pain in ME/CFS.

These recently published findings (in the *Journal of Translational Medicine*) relate specifically to a protein called catechol-O-methyltransferase (COMT) which is known to have effects on pain and inflammation, both of which are key features in ME/CFS, as well as in fibromyalgia.

The instructions to build proteins are contained in our genes, but alterations to these genes can change how they operate, and consequently how the proteins function.

These alterations can be genetic or epigenetic. Very simply, a genetic alteration is a change to the DNA in a gene, while an epigenetic alteration is a change to

how the gene behaves.

The aim of this study was to investigate a number of genetic and epigenetic alterations to the *COMT* gene in patients with ME/CFS and fibromyalgia, and whether they were associated with markers of inflammation or clinical symptoms.

Clinical information and blood samples were collected from 28 patients meeting diagnostic criteria for both ME/CFS and fibromyalgia, and from 26 healthy control subjects.

The blood samples were analysed to assess a number of factors: (1) polymorphisms in the *COMT* gene (these are genetic alterations, or mutations); (2) DNA methylation in the *COMT* gene (this is an epigenetic alteration); and (3) levels of several substances (cytokines) associated with inflammation.

The researchers found polymorphisms in the *COMT* gene in patients with ME/CFS and

fibromyalgia, and also to a similar degree in healthy control subjects. The specific patterns of changes corresponded to the level of activity of the COMT protein.

However, the patients with ME/CFS and fibromyalgia had around twice the level of DNA methylation (the epigenetic alteration) as was seen in the controls.

The patients also had significantly lower levels of interferon gamma, which is a cytokine known to play a role in inflammation.

The researchers believe their findings may point to this change in the *COMT* gene as being an important factor in the development of ME/CFS and fibromyalgia.

Higher methylation levels might be associated with lower activity of the COMT protein and worse symptoms, although more research is needed to explore this more closely.



# Postcard from Nevada



In his latest postcard, **Cort Johnson** talks about “riding the long COVID wave” to ensure large-scale funding for ME/CFS

**T**he good news is that long COVID is getting a lot of study, and new insights are produced seemingly every week. That’s encouraging given that respected researchers like Avindra Nath have stated they believe that if you solve one of the ME-like diseases (long COVID, ME, fibromyalgia, etc.), you’ll solve them all.

The bad news, though, is that the ME/CFS field, with its meagre funding, will likely struggle to

apply the insights gained in an efficient and timely manner. While the long-term trajectory is unquestionably good, who wants, after all these years, to wait for the long term?

Moving forward rapidly is going to require changes though. While the small ME/CFS research field has been great at producing small studies that provide crucial insights, the field has been missing a vital element – big follow-up studies that can really move a field forward.

Recent studies from the US NIH funded ME/CFS research centres demonstrate why big, expensive studies are so important. Small studies have been uncovering gut issues in ME/CFS for over 10 years, but it wasn’t until two large NIH funded studies – both containing over 200 participants – produced similar results that the gut findings in ME/CFS really made a bang.

The conservative NIH hailed the findings twice – in a news release and an NIH Director’s blog



Cort Johnson

– and suggested that a long-sought-after biomarker may have been found. The results were subsequently picked up by many news outlets.

In the NIH Director’s blog, Lawrence Tabak clearly illuminated the problem ME/CFS has faced. Tabak pointed out that “while earlier studies also had pointed to a role for the gut microbiome in ME/CFS... those studies were limited in their size and ability to tease out precise microbial differences”. The bigger studies, though, provided a “solid lead” which Tabak suggested could lead to treatment trials – a rare statement from a risk-averse NIH which does not currently allow its ME/CFS section to fund treatment trials!

These big studies blow a hole in the idea that ME/CFS is some sort of “wastebasket disease” that is not amenable to study, and demonstrate that, if ME/CFS researchers can get their

hands on the resources that other diseases typically get, then swifter progress can be made.

They also demonstrate how critical governmental funding is. While charities can and do provide crucial insights into

diseases, only government agencies like the Medical Research Council in the UK and the NIH have the resources to turn those insights into broad and sustained research efforts.

Yet, while interest in ME/CFS has mushroomed, funding for the disease in the States and elsewhere largely remains at the same low level. In the States, this is partly because of an archaic

***“Only government agencies have the resources to turn crucial insights into sustained research efforts”***

and inefficient funding mechanism that relies on the goodwill of its Institutes – none of which have (or want) responsibility for ME/CFS. In the UK, the Medical Research Council’s statement that “Supporting and enabling a strong portfolio of ME/CFS research has been a high priority for the MRC” seems almost laughable given its pitiful funding over many years.

Unfortunately, ME/CFS belongs to a suite of diseases (also including fibromyalgia, irritable bowel syndrome, migraine, environmental illness, interstitial cystitis and vulvodynia) that have historically been woefully neglected by governmental funders. These diseases are also prevalent, primarily affect females, cause high rates of pain, fatigue and economic losses, are largely invisible, and rarely result in death.

Take ME/CFS – prior to the COVID pandemic it was estimated to affect roughly 1 to 2 million people in the USA, and cause upwards of \$25 billion of economic losses every year. It receives \$17 million or roughly \$10 per person per year in NIH funding. ME/CFS’s sister illness, fibromyalgia, affects roughly 4 million people and receives about \$14 million in NIH funding or roughly \$3 per person per year.

Compare that to multiple sclerosis (MS), a visibly disabling disease that is significantly less functionally impairing than ME/CFS. MS affects about a million



people in the USA, and receives \$131 million in NIH funding or about \$130 per person a year – thirteen times as much as ME/CFS and 40 times as much as fibromyalgia.

There are signs, though, that things may slowly be changing. The £3.2 million 2020 DecodeME study – the world’s largest ME/CFS genomic study which is co-funded, it should be noted, by the MRC and the NIH – stands out as the kind of large, ambitious federally funded study this disease needs.

Recent events also suggest that the message that some major diseases are seriously underfunded may slowly be getting through. The new billion-dollar Advanced Research Projects Agency for Health or APRH-A agency in the USA was designed to be a more nimble and equitable alternative to the NIH.

Time will tell what will happen with ME/CFS and this

agency, but one of its mandated requirements – to prioritize its investments based on “disease burden, including unmet patient need(s)” – would seem to place ME/CFS right in its cross-hairs.

Similarly, one section of the European Parliament’s Horizon Europe 2023–24 work programme focuses on “insufficiently researched” diseases that demonstrate “high prevalence”, are “insufficiently understood, inaccurately diagnosed or treated” and which “represent a high burden for patients and society”. The three examples given are chronic fatigue (ME/CFS), Lyme disease and back pain. The total budget for the 2024 program – €25 million or £22 million) suggests that ME/CFS may soon be getting some more attention.

The massive and unique pool of resources present in governmental institutes demonstrates why advocacy efforts targeting

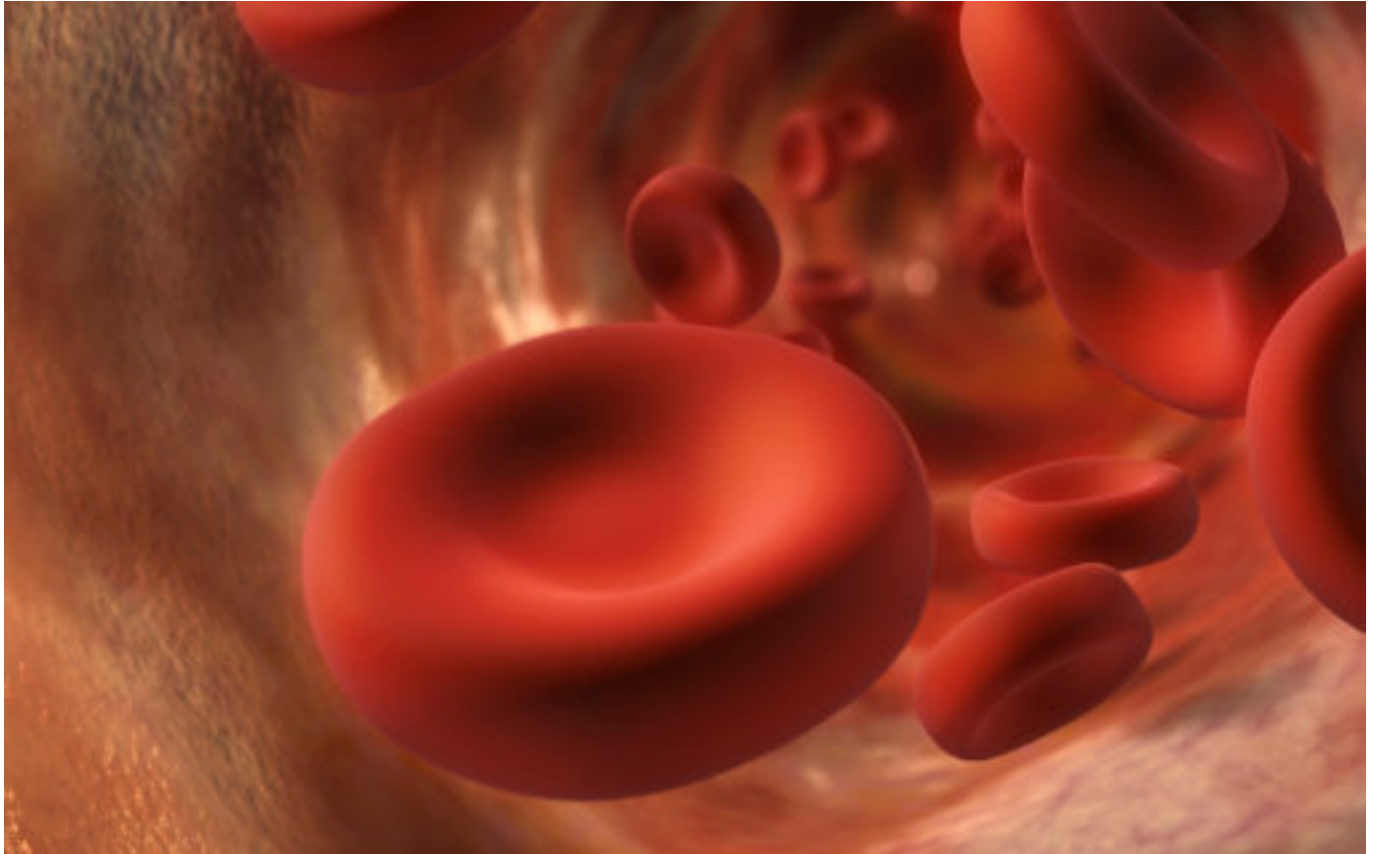
these resources are essential. Left to themselves, organisations like the NIH or Medical Research Council tend to be conservative, but they can be moved by legislative efforts and strong advocacy. It should be noted that the \$1.15 billion the NIH is spending on long COVID came not from inside the NIH (which did nothing for long COVID on its own) but from concerned members of Congress.

Simply getting ME/CFS cohorts into major long COVID studies could make a huge difference, and efforts are underway to do that. With long COVID funding booming and interest in ME/CFS up, we must continue to make clear the compelling connections between ME/CFS and long COVID, and find a way to ride the long COVID wave to plentiful funding. For the first time ever, ME/CFS could be on the road to finally get its proper share of the medical pie.

# Research bites

Our round-up of recent research from around the world

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## Endothelial dysfunction in ME/CFS

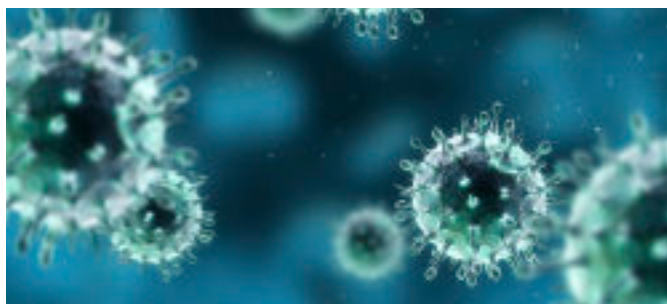
*Sandvik et al., PLOS ONE, 2023*

There is considerable evidence of cardiovascular abnormalities in people with ME/CFS, including dysfunction of the endothelium. The endothelium forms the inner lining of every blood vessel, and is involved in controlling the blood flowing through them. This new study from Norway used two different techniques (flow-mediated dilatation and post-occlusive reactive hyperaemia) to measure the function of both large and small blood vessels in 39 people with ME/CFS and a group of healthy controls. These measures of blood vessel function rely on adequate endothelial function.

Both large and small blood-vessel endothelial function were impaired in the ME/CFS patients,

and these findings confirm those of a previous ME Research UK-funded study using the same techniques. Importantly, this provides greater certainty that there really is a consistent abnormality in endothelial function in people with ME/CFS.

The researchers also assessed the patients after they had been treated with rituximab for 18 months. Although rituximab is not effective as a treatment for ME/CFS, the patients did experience a small improvement in clinical symptoms, and there was similarly a small improvement in blood vessel function over the treatment period. The authors conclude that at least some people with ME/CFS have reduced vascular endothelial function.



## Human herpesviruses part 1

*Rasa-Dzelzkaleja et al., J Transl. Med., 2023*

Viral infections have long been suggested as a trigger of ME/CFS, and human herpesviruses are particularly implicated. Researchers from Latvia have reported that infections with two types of herpesvirus (HHV-6A/B and HHV-7) and one type of parvovirus (B19V) were more likely to be in an active phase in ME/CFS patients than controls. Patients also had a higher viral load and higher levels of pro- and anti-inflammatory cytokines. They conclude that these infections may influence the development and severity of ME/CFS.



## Transcriptomics of PEM

*Van Booven et al., Int. J Mol. Sci., 2023*

Post-exertional malaise (PEM) is a cardinal symptom of ME/CFS, and is top of the recent PSP list of priorities for research. This study from the USA sought to investigate the transcriptomic changes (which cellular processes are active) occurring during exercise and the onset of PEM. One important finding was that ME/CFS patients had dysregulated immune signalling and dysfunctional cellular responses to stress in the recovery period after maximal exercise – this is the period when PEM starts. These results are hopefully a good basis for further research and to identify treatments for PEM.



## Human herpesviruses part 2

*Kasimir et al., Front. Mol. Biosci., 2022*

Dr Bhupesh Prusty and colleagues in Würzburg, Germany are also interested in human herpesviruses. One of their ideas is that HHV reactivation leads to the expression of microRNAs, which in turn cause a reduction in mitochondrial function. They recently examined brain tissue from three ME/CFS patients and found abundant HHV microRNA in various regions (but not in controls). HHV activity in the brain could disrupt nerve function and account for some of the symptoms of ME/CFS, including brain fog, tiredness and pain.



## Misdiagnosis

*Malato et al., Diagnostics, 2022*

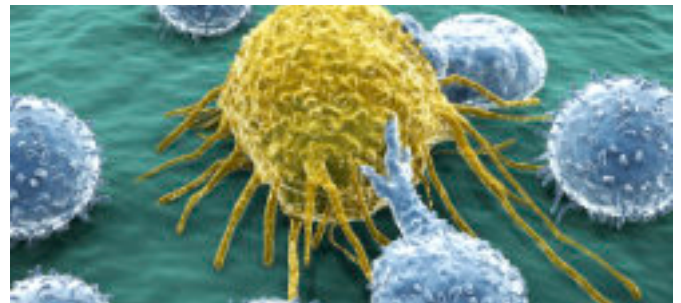
Misdiagnosis is a common problem in ME/CFS, and studies have reported that a significant proportion of patients are eventually diagnosed with other conditions. How might this affect the validity of research into ME/CFS? This analysis from Portugal used statistical modelling to show that a research study investigating associations with ME/CFS would need 500 to 1,000 individuals in each study group to compensate for the possibility that some participants have been misdiagnosed. Further confirmation that finding answers in ME/CFS needs large studies, and therefore large-scale funding.

# A gut biomarker?

*Guo et al., Cell Host & Microbe, 2023*

The microbiome refers to the collection of around 100 trillion microorganisms, including bacteria, that live on or inside the human body. Many of these bacteria are beneficial to us and essential to our survival. In the gut, they live on the membranous lining and break down our food and help protect us against infection. This whole area has become a hot topic of research in many diseases, including ME/CFS, but could the gut microbiome provide a biomarker for the disease?

That's the tantalising prospect of a new study from researchers in the USA who found that multiple measures of the gut microbiome were altered in ME/CFS patients versus control subjects. In particular, levels of *Faecalibacterium prausnitzii* and *Eubacterium rectale* were reduced in ME/CFS. These bacteria are both involved in the production of butyrate, an anti-inflammatory that has a significant impact on gut health. One consequence may be an impaired inability to control bacterial growth, and the researchers talk about a microbial network disturbance in ME/CFS. Cort Johnson discusses these findings in more detail on his HealthRising blog: [bit.ly/3EqKJ5r](https://bit.ly/3EqKJ5r)



## Risk factors

*Palacios et al., Scientific Reports, 2023*

Scientists from the USA have been exploring the potentially controversial question of whether ME/CFS is just a more extreme form of fatigue. They conducted a questionnaire on symptoms in US female nurses, and found that the risk of severe fatigue was increased in individuals who were older, had a higher BMI, used hormone therapy, and had an increased alcohol intake. These risk factors were not associated with ME/CFS, however. The authors conclude that “ME/CFS has a qualitatively different underlying biology from the more common state of severe fatigue”.

## Altered lymphocytes

*Maya et al., Int. J Mol. Sci, 2023*

A new study from researchers at Cornell University tackles the increasingly relevant topic of the immune system in ME/CFS. They conducted a number of experiments on lymphocytes (a type of white blood cell), specifically looking at fatty acid oxidation, which is a stage in the metabolism of the cell. This process was altered in three types of lymphocyte from ME/CFS samples, particularly when energy demand was high. The authors suggest that their findings support the idea of metabolic dysfunction in ME/CFS immune cells, which have an impact on the cells' immunological function.



*“Multiple measures of the gut microbiome were altered in ME/CFS”*



### MicroRNA biomarker?

*Nepotchatykh et al., Sci. Rep., 2023*

While ME/CFS and fibromyalgia are distinct conditions, they do have many overlapping symptoms. Since neither disease currently has any validated biomarkers, they are both often misdiagnosed. Canadian researchers have now identified a pattern of 11 microRNA expression profiles that they say can discriminate between patients with ME/CFS, those with fibromyalgia, and those with both conditions. MicroRNAs are molecules which help cells create proteins, and the ones used here have all previously been associated with ME/CFS. We will wait to see whether they really can form a useful biomarker.



### Gastrointestinal symptoms

*Steinsvik et al., Scan. J Gastroenterol., 2023*

Although not considered a core symptom of ME/CFS, gastrointestinal problems are reported by people with the disease, and they are not well understood. Researchers in Norway examined 20 patients with ME/CFS and abdominal complaints, and performed ultrasound measurements of the stomach. The key finding was that the patients showed signs of impaired gastric accommodation after a liquid meal. This essentially means that the stomach was not able to relax properly to allow for the intake in food, leading to a feeling of fullness and bloating.



# Fundraising stories

Recent fundraising activities by our supporters.  
To support ME Research UK, please visit our website for ideas.

## Ultra marathon

Lizzy Hodcroft is tackling the inaugural 50 km Yorkshire Wolds Ultra in July in aid of ME Research UK. The event's circular route starts and ends on the edge of Pocklington, and takes in some of the best parts of the Wolds, including the villages of Bishop Wilton and Kirby Underdale. Lizzy is running for us because her sister has ME and, as she says, "Running an ultra marathon is an incredibly challenging and rewarding

experience. It is much longer than a standard marathon and can involve climbing mountains, navigating rugged terrain, and running in hot, cold and wet conditions. It requires a great deal of mental and physical preparation, and the rewards come from pushing yourself to your physical and mental limits." [bit.ly/3HZyoWR](https://bit.ly/3HZyoWR)

## Blue Sunday

Anna Redshaw's annual Blue Sunday Tea Party For ME will

be held this year on Sunday 14 May, and is taking place in aid of various ME charities including ME Research UK. There is no set time and the event runs all day. Participants are encouraged to wear something blue, enjoy some tea and a slice or two of cake, and donate the price they would normally pay in a café to an ME/CFS charity instead. You can also join others online as they do the same, and share photos on Facebook. [bit.ly/3YW78PX](https://bit.ly/3YW78PX)



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### Leeds marathon

Laura Wilkinson Hewitt will be running in May's inaugural Rob Burrow Leeds Marathon 2023 in aid of ME Research UK. The event is named in honour of former Leeds Rhinos rugby player Rob Burrow who was diagnosed with motor neurone disease in December 2019. The marathon will see over 10,000 participants take on a brand new

route through Leeds that starts and finishes at Headingley Stadium – the home of Leeds Rhinos rugby league club. [bit.ly/3xps7i9](https://bit.ly/3xps7i9)

### London marathon

Another of this year's marathon runners is Mark Godsolve who will be running the TCS London Marathon on 23 April to raise money for ME Research UK,

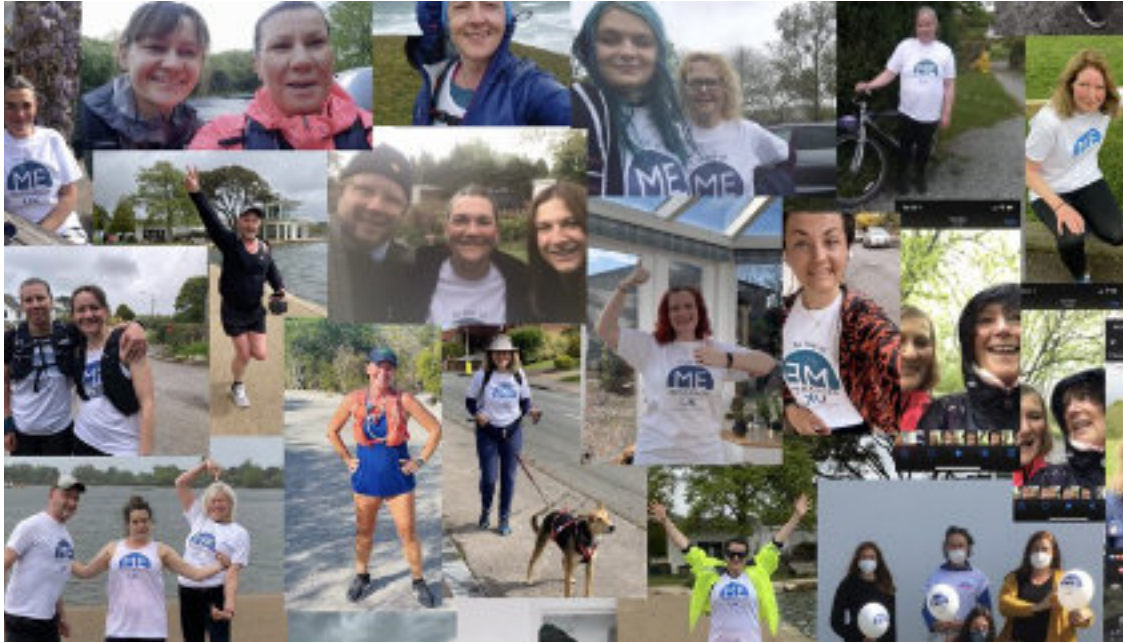
and in memory of his late father who ran the marathon in 1995. Mark's brother, Tim, has suffered from ME for 34 years and so ME research is a cause close to his heart. Ultimately, Mark hopes to get the London Classics medal for finishing all three of the London Marathon, RideLondon-Essex 100 and Swim Serpentine two-mile swim. [bit.ly/3YvVWJL](https://bit.ly/3YvVWJL)

**01 Lizzy, Laura and Mark** are all running marathons this year

**02** Treat yourself to some tea and cake in May

**03 Mark Godsolve** has set himself a challenging target

## RECENT FUNDRAISING



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### Run for ME

Run for ME 2023 has been launched by Claire Carter. “We are a small group of parents, friends and family of someone living with ME/CFS. In May, as part of ‘Walk for ME’, we will be doing a sponsored run or walk to raise awareness, show support and raise funds towards much needed research.”

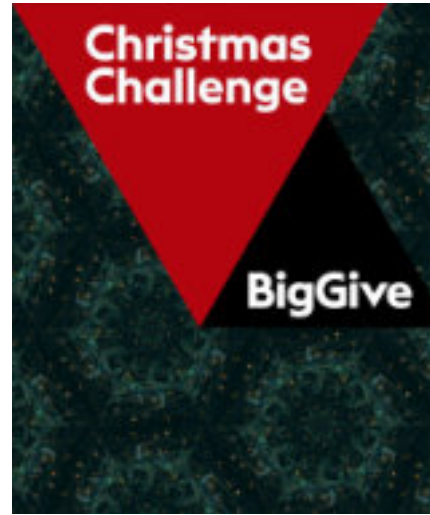
### Penguin challenge

Céline Moyes’ ‘Penguin Challenge in aid of ME

Research UK’ just got a lot harder as she has also taken on the Gold Penguin Challenge which requires her to wild swim throughout the winter months, covering at least 1,000 m per month and including at least two 250-m swims. Swimming in the North Sea in the East Neuk of Fife this is certainly not for the faint-hearted. [bit.ly/3Ecgtv4](https://bit.ly/3Ecgtv4)

### Big Give

We realised it was a big ask for last November’s Big Give, but



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**01** Participants in a previous Run for ME

**02 Celine Moyes** braves the North Sea this winter

**03** Thank you to all who supported the Big Give

our wonderful supporters topped the fundraising target we had set of £7,000. This is our best result yet from the annual fund-matching scheme, and when this total was added to that matched by our pledgers, the total amount raised was a fantastic £19,410! Thank you so much to everyone who pledged and donated, and helped make the Big Give a rousing success for ME Research UK, raising valuable funds for the charity and allowing us to support more crucial research.

# Standing Order Form

To support our work, please consider setting up a standing order by completing this form and sending it to: **ME Research UK, The Gateway, North Methven Street, Perth, PH1 5PP**

☐ Please tick this box to indicate you are happy for us to collect and store your personal information, in accordance with our Privacy Policy at [meresearch.org.uk](http://meresearch.org.uk).

## Name of account holder(s)

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## Instruction to your Bank or Building Society

To the manager, Please arrange to debit my/our account with the amount detailed below, once every month until further notice.

## Account number

## Branch sort code

## Address and postcode

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## Debit amount (£)

## Payment date each month

## Telephone number

## Date of first payment

## Name of Bank or Building Society

**Pay to:** Virgin Money, St John's Centre, Perth, PH1 5UH, UK, Account: ME Research UK, a/c no: 50419466, Branch code: 82-67-09

## Branch address and postcode

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☐ **Tick** if you would like us to treat this, any future donations to ME Research UK (SC036942), and all payments in the previous 4 years, as Gift Aid donations, meaning your donation can increase in value by a quarter at no extra cost to you. You confirm that you are a UK taxpayer and understand that if you pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all your donations in that tax year it is your responsibility to pay any difference. Please notify us if you wish to cancel this declaration, change your name or home address, or no longer pay sufficient tax on your income and/or capital gains. If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

## Signature

## Date

