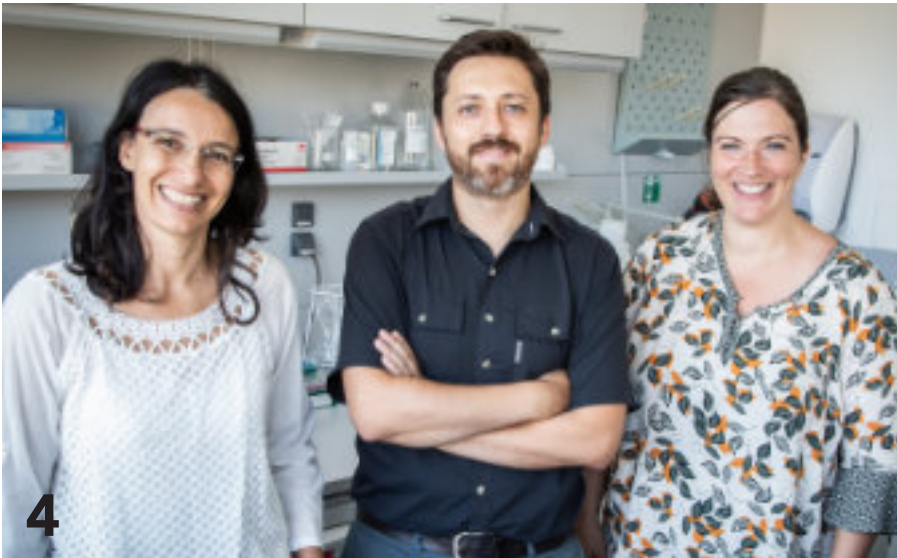


NEWS OF THE ME RESEARCH YOU ARE HELPING TO FUND

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.

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In the spotlight

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

Editorial

Welcome to this issue of *Breakthrough*. I'm delighted that in our twenty-first year, we have now funded over £2.1 million of research projects globally, and have a healthy pipeline of new applications, and the money available to fund those that pass our rigorous scientific review process.

We are now hopefully emerging from the worst of the COVID-19 pandemic, but we must ensure that any relevant outcomes of research into long COVID that can provide information on ME are harnessed to the advantage of ME research.

We will continue to work tirelessly to inform, influence and invest in research that has the potential to do just that.

As ever, this issue of *Breakthrough* provides a round-up of research across the globe, including three new ME Research UK-funded studies. We also have Cort Johnson's latest article, giving his informed view on the development of imaging technology in studying ME.

As I'm sure you are aware, NICE recently 'paused' publication of the new ME/CFS guideline at the eleventh hour. We were hugely disappointed

and remain unclear as to the reasons. As a stakeholder, we have been invited to a roundtable meeting to be held by NICE in mid-October, where we hope to better understand the issues that caused this situation and, more importantly, to represent our position clearly: the guideline (produced after nearly three years hard work by a committee that carefully reviewed all the evidence, and which was subsequently signed off by the NICE Executive) needs to be published as soon as possible.

On a more positive note, we have highlighted some wonderful fundraising stories. A big thank you to everyone who is supporting our work and who have raised funds for us. Without your support and donations, we would not be able to produce this magazine or fund as many studies as we do.

I also feel duty bound to remind you all that Christmas is just around the corner and our 2021 Christmas card selection is now available for purchase.

Thank you and I hope you enjoy this issue of *Breakthrough*.

Jonathan Davies
Chair, Board of Trustees

Christmas Cards 2021

Our Christmas cards are now available.

There's a great selection to choose from once again, and residents of GB and the Isle of Man can also order online, at shop.meresearch.org.uk.

As always, all the proceeds go to help support the work of ME Research UK.

If you would prefer not to send a physical card, dontsendmeacard.com has a good selection of digital cards and allows you to make a donation.



The Big Give

The Big Give Christmas Challenge is the UK's largest matched-funding campaign, and thanks to our supporters ME Research UK will be able to take part this year.

Supporters have already pledged £1,900, and so the first £1,900 of donations made on the Big Give's website from noon on 30 November 2021 until noon on 7 December 2021 will be matched by the pledgers. One donation – double the difference.

There is also the chance that we will be chosen for Charity Champion funding, which will add a further £1,900 to the pledge pot. All funds raised will be invested in ME Research globally.



Monika Riederer, Francisco Westermeier and Jennifer Blauensteiner

New research from Austria

Endothelial dysfunction in ME/CFS

Some of the first research supported by the nascent ME Research UK more than twenty years ago was conducted by a team at the University of Dundee looking at blood-vessel function and the endothelium in people with ME/CFS.

So, since this is an area in which we have a long-established interest, we were keen to support Dr Francisco Westermeier and his colleagues at FH Joanneum University of Applied Sciences in Austria in their plans to look at endothelial function in ME/CFS in more detail.

The first fruits of this research were published in the journal *Scientific Reports* earlier this year, in an article written by Dr Jennifer Blauensteiner.

Inflammation is part of the body's defence mechanism and

healing process, and involves an increase in blood flow to an injured area, in order to bring protective immune cells into the tissue to combat infection and repair damage.

But sometimes inflammation can persist for longer than required, or be triggered unnecessarily, and this may itself cause damage.

Inflammation appears to affect a subgroup of patients with ME/CFS, and has been implicated in other conditions affecting the cardiovascular system, specifically its impact on the endothelium.

The endothelium is a layer of cells lining every blood vessel, and is involved in controlling their opening and closing, and hence the amount of blood flowing through them.



One of the ways the endothelium controls blood flow is through the release of a chemical called nitric oxide.

Dr Blauensteiner used samples from the UK ME/CFS Biobank to look at levels of circulating microRNAs, which are molecules that help cells control what proteins they make.

She found that levels of five of these microRNAs were increased in people with ME/CFS compared with control subjects. Furthermore, these five microRNAs are all involved in controlling the endothelium, specifically via the pathway that generates nitric oxide.

These findings provide more evidence of endothelial dysfunction as a significant factor in the pathology of ME/CFS, but also raise the possibility that these microRNAs may represent biomarkers to distinguish between different patient groups.



The power of collaboration

Funding from the Irish ME/CFS Association

ME Research UK is proud to have been chosen by members of the Irish ME/CFS Association to receive a grant for our research work. The €9,000 received will aid us in funding more research worldwide – research which would not happen without the continued support of our friends.

Since 2018, we have received €21,000 from the Association and we are most grateful as this builds upon a long and successful collaboration. Apart from our own funded projects, we have also co-funded several studies

with allies such as the National Institutes of Health, the Medical Research Council and the Gordon Parish Charitable Trust.

Collaboration allows research which might never have happened to become a reality, and with our scientific knowledge and contacts worldwide, ME Research UK is uniquely placed to nurture new projects and to introduce new researchers into the field of ME/CFS study.

This model ensures that monies entrusted make a real difference to research into ME/CFS.

Shopping online

Do you know that when you're shopping online you could also be raising funds for ME Research UK, at no extra cost to you?

Visit smile.amazon.co.uk and select ME Research UK as your chosen charity, or use easyfundraising.org.uk which hosts some of the UK's best online stores.

Not only will you be accessing some great deals, but you will also be raising funds for ME Research UK without costing you an extra penny.



Pause on NICE guideline update

August publication delayed due to “issues raised”

We had hoped to be able to bring news of the much-anticipated update to NICE's ME/CFS guideline. But, disappointingly, publication was paused just hours before it was due to be released.

In its press release, NICE made mention of “issues raised during the pre-publication period” and that they had “not been able to produce a guideline that is supported by all”.

No further details are given, but we can only conclude that

NICE's independent, evidence-led process has been delayed or halted by those not prepared to accept change. Early drafts of the guideline suggested that CBT and GET – which are no longer supported by the scientific evidence – are to be greatly downplayed from the 2007 guideline.

As a stakeholder in the process, ME Research UK is extremely disappointed and concerned by this turn of events. Patients and doctors deserve up-to-date guidance based on the

most recent scientific evidence about ME/CFS, and this delay will potentially hold up still further the desperately needed improvements to patient care.

ME Research UK is now working with the organisations within Forward-ME to get this important new guideline published as soon as possible.

NICE has promised to “hold conversations with professional and patient stakeholder groups” and we hope to be able to report on this soon.

OUR CURRENT PROJECTS

THE FULL PICTURE



11
PROJECTS



7
COUNTRIES



4
SCIENTIFIC AREAS



£850,000
INVESTED



11 PROJECTS IN 7 COUNTRIES



UK

SANJAY KUMAR
JAMES ALLISON
FAISEL KHAN



GERMANY

CARMEN SCHEIBENBOGEN
& NUNO SEPULVEDA



SPAIN

ELISA OLTRA



USA

JARRED YOUNGER
MERCEDES RINCON



AUSTRIA

FRANCISCO WESTERMEIER



AUSTRALIA

LEIGHTON BARNDEN
SARAH ANNESLEY



BELGIUM

JO NIJS &
LODE GODDERIS

4 SCIENTIFIC AREAS



BRAIN AND
NERVOUS SYSTEM



MUSCLE FUNCTION
AND PAIN



HEART AND
CIRCULATION



INFECTION AND
IMMUNE SYSTEM



Bearing fruit

Three **newly funded studies** have recently started, all made possible by your invaluable support

Over the last few months, ME Research UK has been delighted to award funding to three exciting new research projects, covering a range of different areas of ME/CFS biology.

It is perhaps also worth noting that these grants push the total invested by the charity since our formation to over £2 million, and we are looking forward to the insights into ME/CFS this new research will bring us.

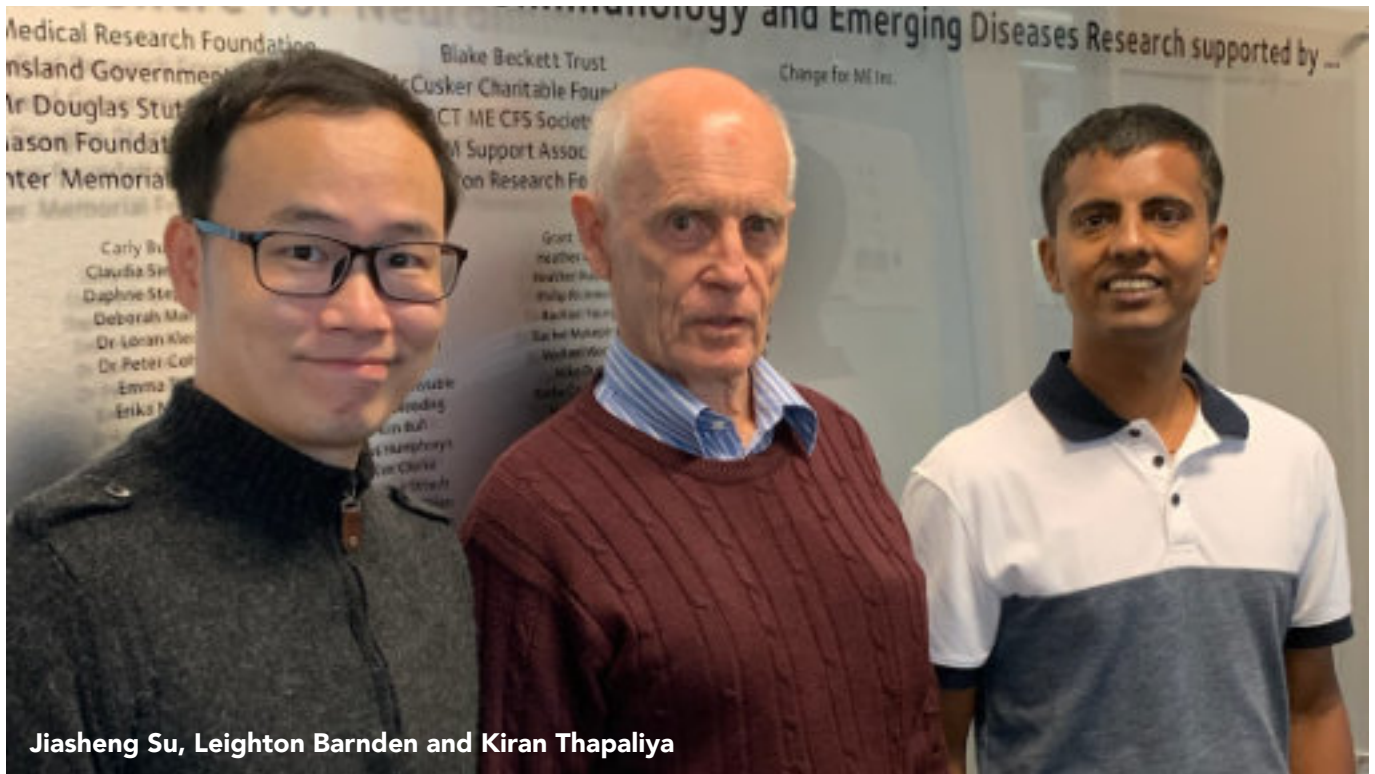
Brainstem

We start in Queensland, Australia, at the laboratory of Dr Leighton Barnden and his team at Griffith University, who plan to use magnetic resonance imaging (MRI) to look at brainstem dysfunction in ME/CFS.

Many of the symptoms experienced by people with ME/CFS – including problems with concentration, memory, vision and heart-rate control – suggest abnormalities in the brain and nervous system. Dr Barnden has

been particularly active in this area, using MRI to reveal a number of findings.

In particular, he found that changes in the structure of the brain were correlated with measures of nerve function within the reticular activation system (RAS) of the brainstem. The RAS is a network of small, interconnected nerves with important regulatory functions, affecting attention, sensory perception, cognitive performance and memory, all of which are deficient in ME/CFS.



In addition, deficits in connectivity between RAS nuclei were confirmed, all of which suggests that nerve signalling in the brainstem is impaired in ME/CFS.

To date, Dr Barnden's results have been limited by the strength of the magnet used in his MRI scanner. While 3-Tesla MRI is commonly used and works well in clinical practice, a stronger magnet such as 7-Tesla allows far more detailed images to be obtained, which can be very valuable in research.

He therefore plans to repeat many of his previous measurements using a stronger 7-Tesla MRI scanner, which will provide increased sensitivity and resolution, and hopefully uncover more information about the RAS in people with ME/CFS.

The team will also test associ-

ations between RAS connectivity and various clinical parameters, which could provide valuable biomarkers of ME/CFS.

Mitochondria

Also based in Australia are Dr Sarah Annesley and Prof. Paul Fisher from La Trobe University in Melbourne. This group's research interests are focused on the role of the mitochondria in neurological conditions such as Parkinson's disease, Alzheimer's disease and ME/CFS.

Found in most cells in the body, mitochondria are small structures whose main role is to convert energy from the food we eat into a form that cells can use, namely molecules called ATP (adenosine triphosphate). For this reason, mitochondria are often referred to as the power plants of the body.

Since a profound lack of energy – a feeling that the muscles are completely drained – is such a common experience of people with ME/CFS, it seems likely that there is something wrong with this complex process of energy storage and production. Indeed, there is a wealth of research evidence suggesting that the mitochondria are dysfunctional in ME/CFS.

Dr Annesley has found this in her own research, showing that the final stage of ATP production in the mitochondria was less efficient in ME/CFS cells than in healthy cells. This final stage involves an arrangement of proteins called complex V. The team also found that the activity of TORC1 (an enzyme which regulates this process) was elevated to compensate.

These experiments were con-



Sarah Annesley



James Allison

ducted in white blood cells called lymphoblasts, which are part of the immune system that protects us from infection and disease. But are these mitochondrial abnormalities also found in other types of cells from people with ME/CFS, which would indicate a more systemic problem?

This is the main question that Dr Annesley hopes to answer in her new study, in which she will determine if these abnormalities in mitochondrial energy production are also present in fibroblasts, which are cells found in the skin. She will also evaluate whether the alterations correlate with the severity of ME/CFS.

In addition, the team will look at whether other cellular pathways are involved, and whether the persistence of these abnormalities is due to epigenetic changes (how specific genes are turned on or off).

A better understanding of mitochondrial dysfunction in ME/CFS may help in the development of diagnostic tests for the

disease, and to identify effective pharmacological treatments.

Muscle pain

In the UK, Mr James Allison is an oral surgeon at Newcastle University, whose interest lies in the widespread muscle and joint pain suffered by many people with ME/CFS, and which has a huge impact on their everyday activities and quality of life.

While central sensitisation in the brain and dysfunction of the autonomic nervous system (ANS) are thought to play a role in this pain, the precise mechanisms involved are not yet known.

Temporomandibular disorders (TMDs) are a group of musculoskeletal conditions affecting the muscles that move the jaw. They cause pain in the face and jaw, and are more common in ME/CFS than in the general population. Research from Prof. Newton's group at Newcastle University suggests that the link between ME/CFS and TMDs may be due to a common under-

lying problem affecting the ANS.

The ANS controls many of the unconscious activities of the body such as breathing, heart rate and the circulation of blood. It is known to work less well in ME/CFS, and is worse still when TMD is also present.

Mr Allison plans to use electroencephalography (which measures the electrical activity of the brain non-invasively) to assess the brain's response to painful pressure applied to the finger and jaw in four groups of people, including patients with ME/CFS and/or TMD, and healthy participants without either condition.

The idea is that these responses will help to determine how pain differs in ME/CFS and in other people. Other experiments will attempt to identify where in the brain these differences are located, and investigate whether the ANS can be 'calmed' by non-invasive stimulation of the vagus nerve, which might help inform future treatments for pain in ME/CFS.



Postcards from Nevada



In his latest postcard, **Cort Johnson** looks at how imaging technology has enabled a better understanding of the brain in ME/CFS

We know the brain as the seat of consciousness, thinking and our emotional lives. But it's actually much more than that as the brain controls so many of the conscious and unconscious functions of the body.

So the cognitive, sensory, sleep and mood problems found in ME/CFS, but also the pain and post-exertional malaise that are characteristic of the illness, all involve the brain.

However, the most important organ in the body is also, unfortunately, its most opaque, and we need to rely on imaging techniques to explore it in any detail.

Brain scans come in several different flavours, but the most versatile and most commonly used one in diagnostic medicine and research is magnetic resonance imaging (MRI).

MRI was developed in the 1970s and continues to be refined today. It uses magnetic fields and radio waves to produce

crisp, detailed, two- and three-dimensional images of an internal organ, and is commonly used to diagnose conditions and to assess the effectiveness of treatments.

If you've ever had to remove anything metal, and then been rolled into a narrow tube and told to keep still, then you've been in an MRI scanner.

First steps

The first MRI study in ME/CFS was conducted in 1992, and featured some early pioneers of the



Cort Johnson

field – Dan Peterson, Paul Cheney and Anthony Komaroff. These researchers uncovered a mysterious feature – small lesions scattered throughout the brain, which have yet to be explained.

(Avindra Nath recently uncovered similar lesions in COVID-19 patients, and Nath believes that small brain blood-vessel leaks may be responsible for the wide variety of symptoms found in long COVID.)

Since then, several dozen MRI studies in ME/CFS have produced some memorable results. A 2001 study demonstrated a crucial fact – that brain abnormalities in ME/CFS weren't just producing cognitive problems, but were also likely to have an impact on the physical functioning of patients.

Prefrontal cortex

Follow-up studies linked physical functioning to reduced grey-matter levels across the brain and in

the bilateral prefrontal cortex, and the researchers concluded a key role for the central nervous system in ME/CFS.

The prefrontal cortex is one of the most recently evolved areas of the brain, and is involved

in a multitude of functions, including planning, short-term memory, sleep, wakefulness, pain and limbic-system regulation.

A 2017 Australian MRI study killed two birds with one stone when it demonstrated that unrefreshing sleep was not a 'misperception' on the part of ME/CFS patients, but was likely linked to prefrontal cortex problems.

“a key role for the central nervous system in ME/CFS”

A Japanese study linking beta-adrenergic autoantibody levels to reduced prefrontal cortex functioning suggested that an autoimmune response was affecting the brain, while another novel study found that exercise impaired oxygenation in the prefrontal cortex.

Other Japanese researchers have proposed that prefrontal-cortex functioning influences autonomic-nervous-system functioning, movement and the stress response. And a repetitive transcranial magnetic study is now underway, attempting to boost this potentially critical part of the brain in ME/CFS.

Cognitive function

The origin of the mysterious mental fatigue became clearer when an MRI study found that people with ME/CFS needed to use more parts of their brain to accomplish the same tasks as healthy people. Four years later, a similar Japanese MRI study reported that people with ME/CFS had to engage in “a massive mental effort” in order to accomplish cognitive tasks.

Related to this, Dr Leighton Barnden at Griffith University in Australia proposed that the “lower information capacity” found in ME/CFS patients' brains requires more areas of their brain to be recruited. (No studies have found a lower IQ in ME/CFS, but rather there appears to be a lower capacity to process information quickly.)

These studies make it clear that dramatic inefficiencies in brain functioning make thinking a more energy-intensive process in people with ME/CFS.

The brainstem

For the past ten years, Dr Barnden has played a major role



in ME/CFS brain research, and on page 9 of this issue of *Breakthrough* you can read about his newly funded MRI study looking at the brainstem.

In 2011, Dr Barnden began a series of studies on this much-neglected area of the brain, which regulates several important functions such as breathing, heart rate and blood pressure.

Barnden's first MRI brainstem study suggested that grey-matter losses might be producing problems in the autonomic nervous system, while further research found distorted interactions between the brainstem and the seat of the stress response in the brain – the limbic system. Three years later, another MRI study found further evidence of deficits in the brainstem.

Brain connectivity

Thus far, most studies had suggested the existence of neuroanatomical problems in the

brains of people with ME/CFS. But attention then turned to a crucial aspect of brain function – communication and connectivity.

It is now clear that communication issues between different parts of the brain play a major role in central-nervous-system diseases, and they have consistently cropped up in ME/CFS.

One MRI study found that, even during rest, some parts of ME/CFS patients' brains continue to communicate with each other at increased rates – as if they are trying to fix an unresolved problem. That study seemed to set off a trend as more research quickly found further evidence of communication problems in the brain, which researchers were able to show correlated with fatigue.

The future

We aren't nearly finished with MRI studies in ME/CFS. In fact, the best is probably yet to

come. As MRI studies are ramping up in long COVID, Avindra Nath is assessing brain functioning while people with ME/CFS exercise, a Swedish MRI study is looking for structural brainstem and spinal cord problems, a Florida study is documenting exaggerated brain activity in response to pain, and researchers in Baltimore are investigating whether n-acetyl-cysteine supplementation is able to change brain activity.

And of course we have Dr Barnden's new study in which he is looking at the brainstem in more detail using a newly acquired, more advanced MRI scanner.

You can read more about Dr Barnden's plans on page 9, and maybe in a year or two we'll be able to update this article with all the new findings that have flowed from this and other ongoing MRI studies looking at the brain in people with ME/CFS.

Research bites

Our round-up of recent research from around the world

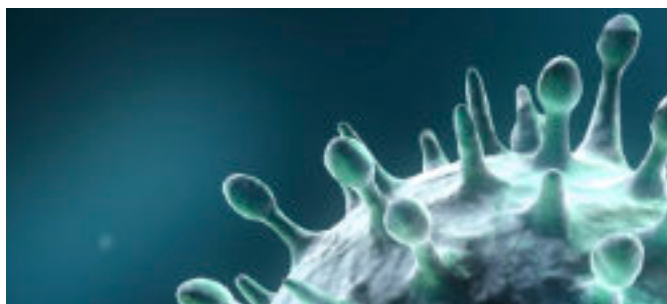


Low-dose naltrexone

Cabanas et al., Frontiers of Immunology, 2021

Naltrexone is a drug that blocks the opioid receptors in the brain. These receptors are part of the natural pain-killing process of the body, so a drug that blocks them would seem like the last thing you'd want to treat a condition such as ME/CFS. However, in low doses, naltrexone appears to be of benefit to some patients, at least, possibly via an anti-inflammatory effect on the central nervous system. There is some evidence from small case series and anecdotal reports that low-dose naltrexone (LDN) can reduce the severity of symptoms in patients with fibromyalgia, multiple sclerosis and ME/CFS, but the drug is still considered experimental for these indications and is not licensed.

This prompted Australian researchers to investigate the potential therapeutic mechanism of LDN in ME/CFS, by looking at its effects in natural-killer immune cells from nine people with the condition and nine healthy control subjects. Treatment of the patients with LDN was associated with improved function of a signalling channel in the immune cells (TRPM3) which is targeted by some opioid receptors, and which has previously been suggested to be important in the development of ME/CFS. These results lend further weight to LDN as a potential treatment for the condition, and highlight the value of a clinical trial to investigate this further.



Herpesvirus reactivation

Lee et al., Frontiers in Medicine, 2021

ME/CFS is often reported to have been triggered by an infection, one theory being that the disease is caused by reactivation of dormant pathogens such as herpesviruses. Researchers at the London School of Hygiene and Tropical Medicine assessed saliva samples from people with ME/CFS, and discovered that the viral DNA load of two human herpesviruses was increased compared with healthy controls. Furthermore, fluctuations in viral load over six months correlated with ME/CFS, lending weight to the theory of herpesvirus reactivation.



Hand-grip strength

Jäkel et al., Journal of Translational Medicine, 2021

Muscle fatigue is a common symptom of ME/CFS, but an objective assessment of this is not currently included in the diagnostic work-up of patients. Hand-grip strength (HGS) is an established measure of muscular strength, and this study showed that several parameters of HGS were significantly reduced in people with ME/CFS, and were associated with disease severity, post-exertional malaise and muscle pain. The authors raise the possibility that assessment of HGS could be a simple and sensitive diagnostic test of muscle fatigue in ME/CFS.



More on herpesvirus

Mozhgani et al., Intervirology, 2021

Another study looking at the link between human herpesvirus (HHV) and the risk of ME/CFS is this systematic review focusing specifically on HHV-6, which has been implicated as a potential cause of the illness. A meta-analysis of eleven studies found that, overall, HHV-6 infection was three-and-a-half times more likely in people with ME/CFS than in the general population. There was considerable variability in results between these studies, but the authors say the results do provide further evidence of an association.



Links with long COVID

Paul et al., PNAS, 2021

The parallels between the symptoms of ME/CFS and those of long COVID have been much discussed. In this helpful review, scientists from John Hopkins University School of Medicine summarise the evidence for biological abnormalities in both conditions, listing redox imbalance, systemic and neuro-inflammation, impaired ATP generation and a general hypometabolic state. Nothing new perhaps, but another indication that intense interest in the COVID-19 pandemic may also ultimately benefit people with ME/CFS, who have been living with these symptoms for far longer in many cases.

Living with severe ME/CFS

Strassheim et al., Healthcare, 2021

Very little research has been conducted in people with severe ME/CFS, and this is largely because their poor health makes it very difficult for them to engage with research studies. They are often not able to attend for hospital visits, and the procedures may be impossible to carry out or have a detrimental effect on their symptoms. It is therefore important to find ways in which to include this neglected group of patients in research, and this is what Victoria Strassheim has been looking at in a series of studies over the last few years.

In this most recent project, which was supported by ME Research UK with funding from the Sophie Miles Bequest and ME North East, five people with severe ME/CFS were interviewed. A detailed analysis of their responses identified three main themes: their lived experience of the illness, challenges to their daily life, and how they manage the condition. The investigators believe these findings highlight factors that place people at greater risk of developing more severe ME/CFS, and hope that these insights will allow research and healthcare communities to engage more effectively with this overlooked population. You can read more at meres.uk/experience.



Diffusion tensor imaging

Thapaliya et al., Eur. J. of Neuroscience, 2021

You can read more about Dr Leighton Barnden's work on imaging in ME/CFS on page 9 of this issue, but another recent study from his group in Australia used diffusion tensor imaging (DTI) to look at the structure of the brain. The advantage of DTI is that it is sensitive to the microstructure of tissue. In this case, the researchers found several abnormalities in different regions of the brain of ME/CFS patients. Significantly, these abnormalities were present in those who met International Consensus Criteria alone, but not in those who met the broader Fukuda definition of CFS.



Symptom fluctuation

McDonald et al., The Patient, 2021

One of the great challenges of understanding more about ME/CFS is the variability in symptoms that people suffer, both between individuals and over time. Australian researchers are planning to investigate this in more detail by assessing a range of factors (including fatigue, other symptoms, potential triggers, mood and cognitive demand) three times a day for up to twelve weeks. This will be done using an electronic diary worn on the wrist. If such a study proves feasible, it may help to give us a better understanding of how ME/CFS symptoms fluctuate and are triggered on an individual level.



Victoria Strassheim

“It is important to find ways to include this neglected group in research”



COVID-19 risk

Malato et al., Heliyon, 2021

Many people with ME/CFS are understandably concerned about their risk of infection with COVID-19. ACE2 is a receptor on the cell surface through which the SARS-CoV-2 virus enters the cell, and it also affects the process by which the virus damages tissue. In this meta-analysis, findings from some studies suggested that the expression of the *ACE2* gene is increased in people with ME/CS. Although there were some inconsistencies, the researchers concluded that this group may be at an increased COVID-19 risk and should therefore be considered a priority for vaccination.



Lipid profiles

Nkiliza et al., Journal of Translational Medicine, 2021

Lipids are essential molecules comprising a number of different types (including fats) which have a range of functions in the body, including being involved in the immune system, inflammation and bioenergetics. Researchers in Florida measured several lipids in blood samples from ME/CFS patients and healthy control subjects. Interestingly, women with ME/CFS had reduced levels of three lipids, while men with ME/CFS had increased levels of four lipids, with some overlap between the lipids involved. This authors suggest that these lipids may be involved in the pathogenesis of the disease.



Aled Edwards (route finder), Paul Magee, Bruce Dickson, Martin Wiseman and Richard Davies

Friends united

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

Celtic Wiseman (Alba)

On 22 August, a team of four friends rode the inaugural Celtic Wiseman (Alba) – a gruelling 116-km cycle ride from Dunbar to Edinburgh. As well as raising the profile of their friend Martin Wiseman who has suffered with ME, their aim was to raise funds for ME Research UK. They have been doing this since 2010 with the Celtic Wiseman Perpetual series of rides in Cornwall, Wales, Ireland and now Scotland. It was therefore fitting

to welcome the team to Scotland for this year's ride. Dunbar was an apt place to begin the adventure, as it is the birthplace of celebrated explorer John Muir. Look out for more photos of the ride in the next issue of *Breakthrough*.

Keep on running

Two supporters who had a very active May this year were Stephen Marlow and Michael Forster. Stephen, whose fiancée Helen has ME, ran in the

Prestwold 5-km race. "I was already entered and thought it would be a good opportunity to raise some money for ME research and raise the profile of the illness. It is my small contribution to the effort."

Michael is part of Walk for ME, and in May he ran a total of 100 miles, to remember every person who has suffered from ME (including his own father), and to raise money for much-needed research. Many thanks to both of them!



01



02

Walk for ME

In the last issue of *Breakthrough*, Luke Remnant explained how he started Walk for ME to raise funds for ME research. And now we can see how the campaign has borne fruit this year, with many wonderful supporters taking part.

It's not just walking of course, fundraisers have also been running, cycling and swimming.



03

Claire Carter's intrepid team tackled anything from 5k distances to marathons. In all cases, they were doing it for their "incredible and inspiring children and young people who battle this devastating illness every day".

Marta Ulrich does not consider herself a sporty person, but she prepared for and ran a 5k for her husband Daniel, who has had ME/CFS since 2017.

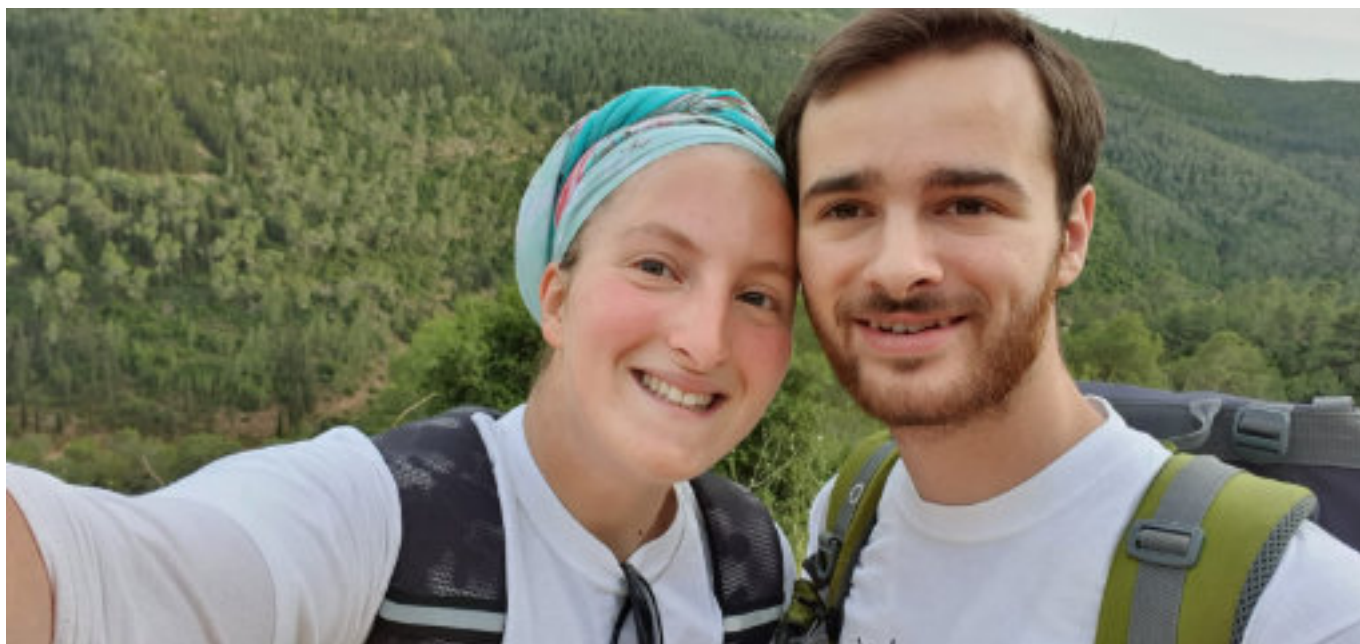
Alex Lee has been lucky enough to be able to swim at a local beach during the pandemic. His goal in 2021 is to swim a total of 191 km, the distance from Belfast to Dublin, raising money for ME research with every stroke.

Thank you to all these wonderful walkers, runners, cyclists and swimmers, who have raised a fantastic total for ME research.

01 The walkers, runners, cyclists and swimmers who make up **Team Run for ME**

02 Alex Lee is fresh from a dip in the Irish Sea

03 Marta Ulrich and husband Daniel



01



02

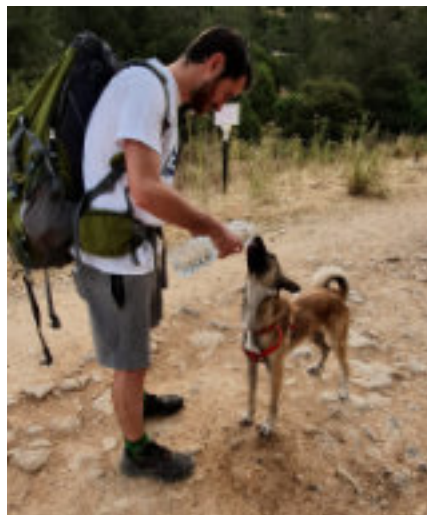
Jerusalem or bust

In May, Miriam Simmonds, her husband Mendy and their dog completed their 25-kilometre trek in aid of ME Research UK (mentioned last issue). The walk took them to Jerusalem, finishing at the Western Wall. Miriam has fortunately recovered from the ME/CFS with which she was diagnosed at age 14, but now she wants to fight for those suffering like she once did. “Those ill with ME/CFS need the medical research and education so that

they can be treated adequately and given the support and treatment they need to overcome the illness.” Thank you so much to Miriam and Mendy for your support.

Doing what you hate

Laura Woods really hates running, so it was a bit of a surprise when she set herself the challenge of running 5 km every day for ten consecutive days. Her aim was to raise money for ME research. Laura says, “A very



03

01 Miriam and Mendy Simmonds en route to Jerusalem

02 Laura Woods certainly looks like she’s enjoying herself

03 Dogs need to keep well hydrated too

close friend of mine suffers with ME and it is heart-breaking to witness someone that is so driven and passionate about life basically watch everything from the side-lines, as this disease means she cannot do very basic things. So seeing as I cannot come up with a cure myself, instead I’m raising some money for ME Research UK.”

Laura completed this amazing target in April. Thank you from all of us at ME Research UK – a fantastic achievement.

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.

Name of account holder(s)

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

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

☐

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

