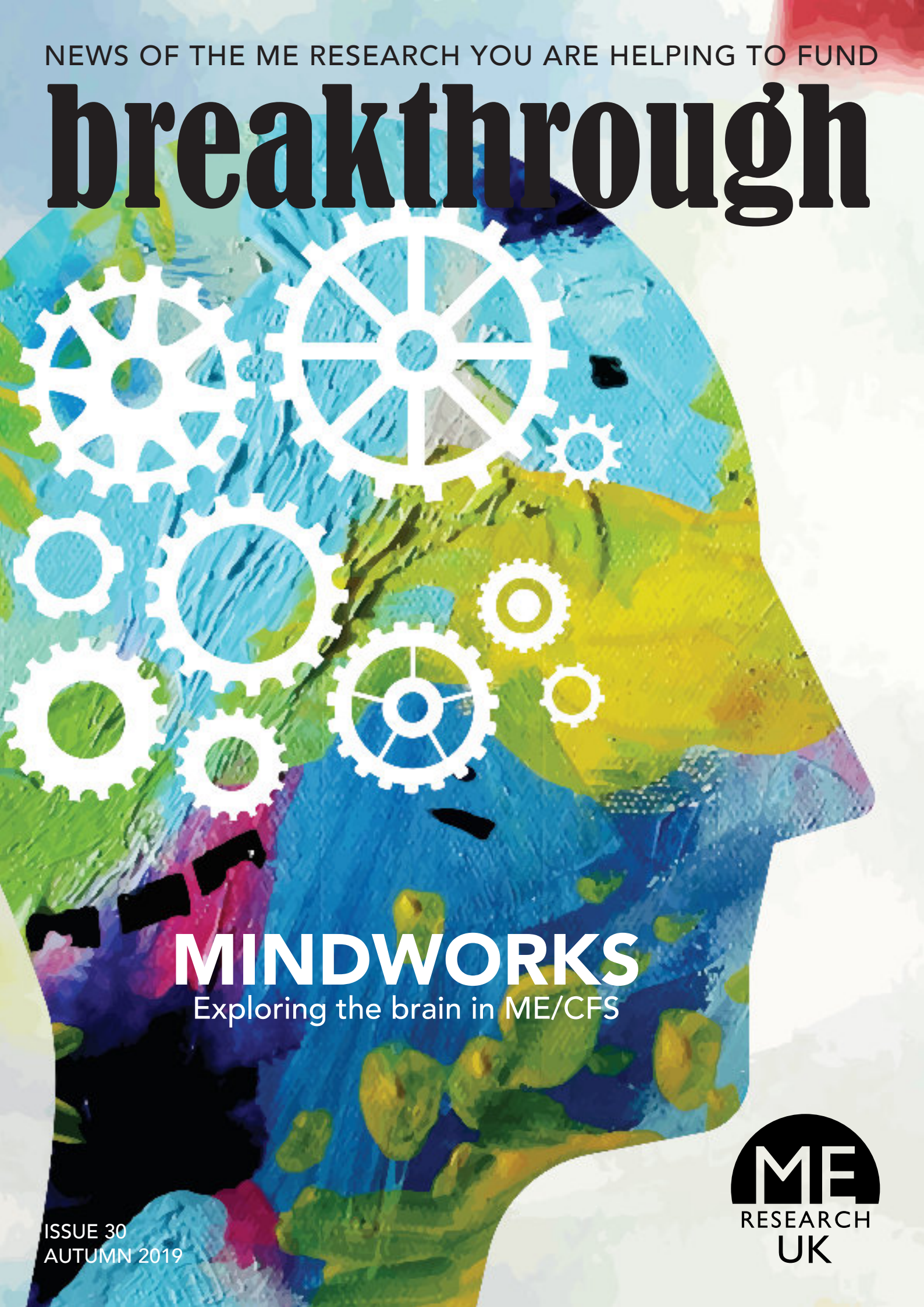
NEWS OF THE ME RESEARCH YOU ARE HELPING TO FUND

breakthrough



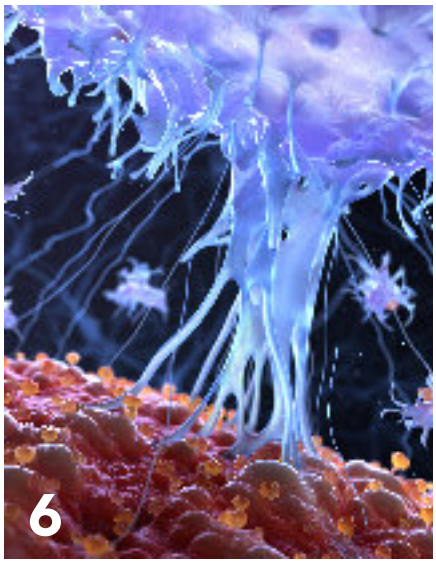
MINDWORKS

Exploring the brain in ME/CFS

ISSUE 30
AUTUMN 2019

ME RESEARCH UK

CONTENTS



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). The charity also aims to energise ME research by identifying potentially important areas for future biomedical research, and 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 this issue

In the spotlight

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

Editorial

Welcome to the Autumn 2019 issue of *Breakthrough* which focuses partly on studies into ME/CFS and the brain from groups in Australia and the UK. This remains a key area of research.

We also say thank you to Dr Vance Spence who, although remaining involved in the charity, has decided to step down from the Board of Trustees. We will certainly miss him at our Trustee meetings, but I can personally vouch for his ongoing commitment and passion about the condition and our organisation, and I look forward to continuing to work with him in the future.

Over the summer months we have been developing our strategic plan. We will continue to fund biomedical research into ME/CFS, as we have done since 2000, but will also now look at providing support to new researchers embarking on careers in ME/CFS. We believe it is important to make the illness an attractive career choice to create a 'pipeline' of new researchers. More on this in coming weeks.

We are currently looking to recruit a new Trustee with key scientific and research skills. Hopefully, the Q&A with Prof. Faisel Khan will offer a brief insight into the role of a Trustee. All research proposals we receive are rigorously reviewed, so it is important we continue to have a strong scientific and research representation on our Board. If you, or anyone you know, would be interested in applying, please check our website for details.

There are also some wonderful fundraising stories as always, and thank you to everyone who is supporting biomedical research into ME/CFS and raising funds for us. Without your support and donations, we would not be able to fund as many studies as we do. Thank you and enjoy the issue.

Simon
CEO, ME Research UK

Legacies

Every year, supporters of many worthwhile causes make an extraordinary difference to their favourite charity by leaving a gift in their Will.

These legacies are an increasingly vital source of funds for charities such as ME Research UK. Every gift, no matter its size, is important to us.

Through a legacy you can make a direct and lasting contribution to our work and help fund scientific research in future years.

If you are interested in supporting us in this way, please visit our website or call our main office number.

Christmas fundraising

Like it or not, Christmas is approaching. But it can also be a good opportunity to support your favourite charities. Here are a few ideas for raising funds for ME Research UK, with many more on our website.

Christmas cards
Our Christmas cards are now available to buy, and there is a flyer with this issue of *Breakthrough*. This year, cards are also available to order online.

Christmas shopping
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.

Christmas party
Organise a Christmas party for your family, friends and/or work colleagues, with the proceeds going to ME Research UK.

The lamplighter

Retirement of Dr Vance Spence

Dr Vance Spence, a founding Trustee and Chairman of ME Research UK for the past 18 years, announced his retirement at the charity's AGM earlier this year. Although standing down as a Trustee, Vance will continue to be a member of our Scientific Committee, providing input and advice on the quality of scientific projects.

As Vance says, "I turned 70 recently and thought it time to hand over to younger heads to take the charity forward. I'll be able to spend time with my grandchildren, and my hobbies such as photography."

All of us – from fellow Trustees, colleagues at the University of Dundee, and ME patients – have been fortunate enough to count on such a warm, skilled and dedicated friend over the past 30 years.

A graduate of the Universities of London and Dundee, Vance was originally a Principal Clinical Scientist responsible for vascular services and research. After a bout of glandular fever in 1980, he began to develop the symptoms of ME and was forced to take early retirement at the age of 41 due to chronic ill health.

Despite his illness, he dedicated his limited energy to helping fellow ME/CFS patients locally; for example, he became Chair-

man of the Fife ME Support Group and was instrumental in forming the Fife Steering Group for ME in 1992. The Group's work finally bore fruit with the formation of the NHS-funded CFS Clinical Service in Fife.

Throughout these years, Vance gave freely, voluntarily and unstintingly of his time for to support many hundreds of people diagnosed with ME/CFS, including writing letters on patients' behalf to official bodies or to trusts to elicit financial support in specific cases.

In 1997, he rejoined the University of Dundee Medical School as Honorary Senior Research Fellow in the Department of Medicine, with the objective of stimulating research into the causes of ME/CFS, which was very much a forgotten illness in research terms. He soon realised, however, that there was a need for a medical research charity dedicated to raising sufficient funds to get projects off the ground.

So, with the help of Roger Jefcoate CBE DL and Robert McRae, a senior banker who also had ME, in 2000 he founded and launched the charity we now know as ME Research UK. Vance not only had the vision to create a biomedical research-driven ME charity, he also had the skills and dedication to make it a reality.

Through his leadership as Chairman, he has steered the charity to become the largest funder of biomedical research into ME/CFS outside North America. To date, without governmental or Lottery funding, £1.6 million has been invested in research projects, mainly in the UK but also in Canada, Germany, Australia, Belgium, Sweden and the USA.

Through his direction, the charity has become highly respected by academic colleagues and a trusted partner in the eyes of scientific researchers in many countries. At the same time, Vance himself has been a much respected advocate for the recognition of ME/CFS, authoring many articles, essays and annotations on various aspects of the illness.

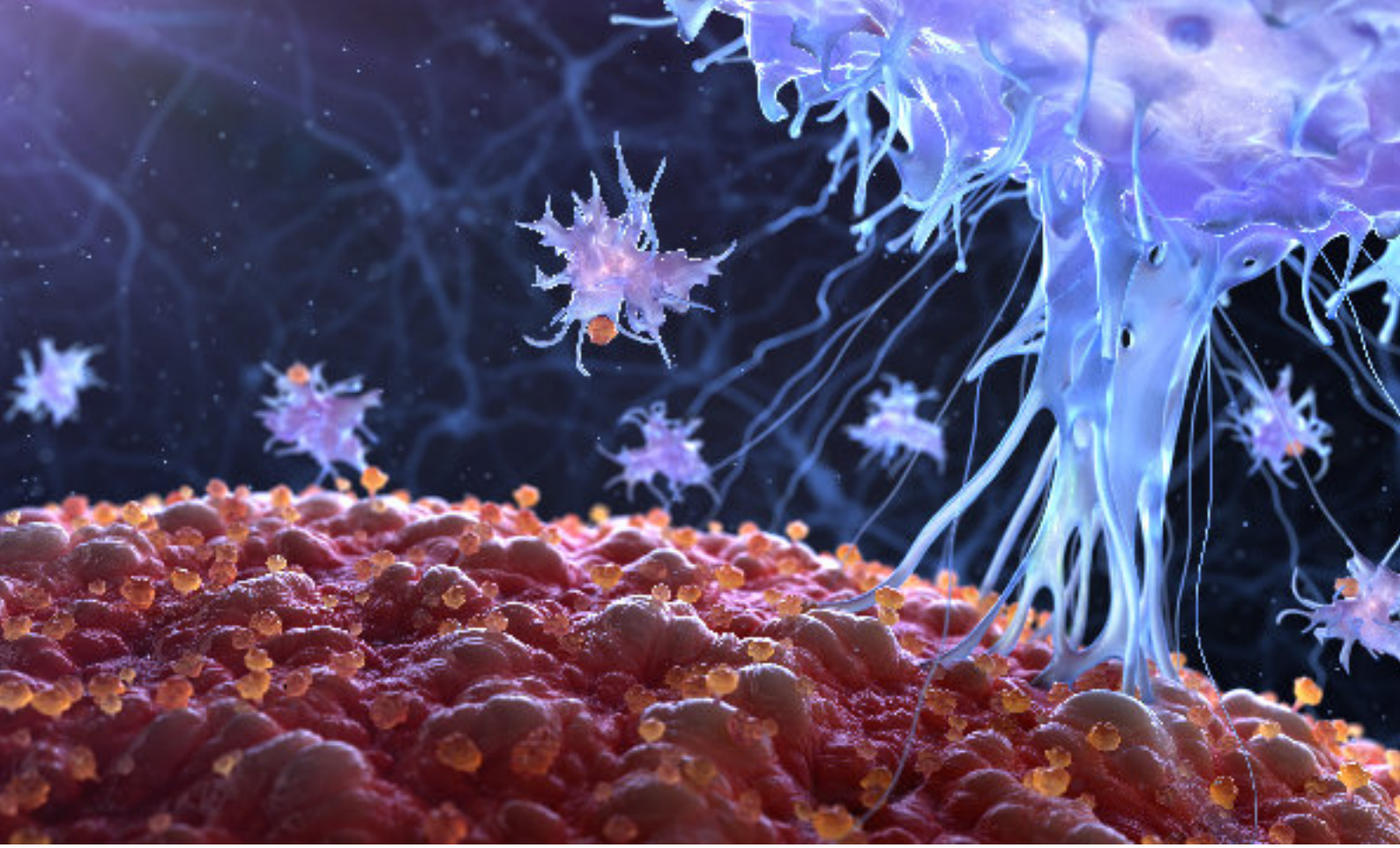
He was instrumental in the formation of the Scottish Parliament Cross Party Group on ME and was a member of the parliamentary Short-Life Action Group on ME/CFS. Despite his illness, Vance was in frequent demand to speak to local ME/CFS Support Groups and to join panels of experts at various gatherings, conferences and events; in February 2018, for example, he was again a guest on BBC Radio Scotland.

In times past, streetlamps were lit each night by a lamplighter who wound his way through every town at dusk. The metaphor of the lamplighter went deep in popular culture; people knew where the lamplighter had been by the light he cast as he walked on, by the little seeds of light he planted as guides for others.

Vance has been a lamplighter. His inspiration and vision have been at the core of the success of ME Research UK since its inception, and his friendship has touched the lives of many thousands, from young scientists wishing to start research into ME/CFS to individual ME patients and their families.

All of us at ME Research UK thank Vance for his leadership over the past 20 years, and wish him a long and happy retirement.

We are fortunate in that Vance has agreed to remain on our Scientific Committee and joins fellow Founding Trustee, Bob McRae, as an Honorary President of ME Research UK.



End of the road?

Clinical trial results confirm rituximab has no clinical benefit in ME

We reported last year the disappointing news that preliminary results from the Norwegian randomised trial of rituximab were not showing any clinical benefit of the drug in people with ME/CFS. The final results of the trial have now been published in the *Annals of Internal Medicine*, and unfortunately confirm these initial indications.

Rituximab is an antibody that attacks B-cells, and has been used to treat some cancers and autoimmune disorders. Following promising results in patients with ME/CFS, a randomised, placebo-controlled trial of rituximab was started in 2014 at five centres in Norway.

One hundred and fifty-one adult patients with ME/CFS (defined according to the Canadian consensus criteria) were treated with either rituximab or placebo over the course of a year, and followed up for a further year.

A total of 26.0% of patients who received rituximab achieved a treatment response (defined as a slight, moderate or major improvement in symptoms), compared with 35.1% of those on placebo, and the difference between the treatment groups was not statistically significant.

There were also no group differences between the treatment groups in other outcomes such as self-reported function and physical activity.

Rituximab has been one of the greatest hopes in recent years for an effective treatment for ME/CFS. But it remains to be seen exactly what this means for the drug as far as ME/CFS is concerned, and for our understanding of the pathophysiology of the illness.

The lead investigator, Dr Øystein Fluge, and his colleagues conclude that: "The lack of clinical effect of B-cell depletion in this trial weakens the case for an important role of B lymphocytes in ME/CFS but does not exclude an immunologic basis."

If this is the end of the road for rituximab, let us hope that it stimulates further research into other aspects of immunity in ME/CFS, like the studies we are currently funding in Vermont, Alabama, Newcastle, and Berlin.

Prof. Faisel Khan

Get to know one of our Trustees

What is your background?
I have worked in biomedical research for about 30 years and am currently Professor of Cardiovascular Sciences at the University of Dundee. My own research has been focused on the cardiovascular system, including several studies looking at its role in the pathology of ME/CFS.

Why did you become a Trustee of ME Research UK?
Mainly so I could be involved in making decisions in a charity that can have a real impact on the lives of people affected by ME/CFS, and to help ensure ME Research UK fulfils its purpose.

What do you do as a Trustee?
As well as being involved in decision making, I also help evaluate scientific research studies that are submitted for potential funding. We want to support high quality research that has the potential to advance our understanding of the underlying biology of ME/CFS and lead to better treatments.

What satisfaction do you get as a Trustee?
I work with a dedicated team of people all focused on improving the quality of life for people affected by ME/CFS, and helping to understand this illness better and find a cure.

Do you know someone with the biomedical knowledge to be our new Trustee?

Maybe it's a consultant you've met or a researcher you've heard about. Or maybe it's you.

ME Research UK exists simply to fund biomedical research projects – to date we have invested over £1.6 million. As we embark on our next 5-year strategy, we plan to add to the scientific knowledge of our Board of Charity Trustees. We are looking for someone keen to use their experience of medicine or biomedical research to help identify the best research projects for us to fund. If you know anyone who suits this role and would be willing to devote time to energising ME research, please pass this on to them or let us know.

To apply, find out more about our work, and understand a Trustee's duties, look under 'About Us' on our website at meresearch.org.uk. Or phone 01738 451234 (daytime) or 07717 224592 (evening/weekend) if you would prefer to talk.

Connect the dots

An Australian group has been looking at **brain function and connectivity in adolescents** with ME/CFS

Cognitive symptoms are very common in ME/CFS, and can be some of the most frustrating problems affecting the daily lives of people with the illness. Since cognitive function is what enables us to gather and process information, abnormalities have a significant impact on our ability to function at home, work or school.

Often collectively referred to as 'brain fog', cognitive symptoms include difficulties with memory, concentration and the sorting of information. These elements have been measured objectively in ME/CFS patients, including in studies supported by ME Research UK.

Brain abnormalities

But can cognitive problems in ME/CFS be traced back to abnormalities in the structure or function of the brain? Limited evidence suggests that it can, but there is still little information about this aspect of the illness – particularly in young people, whose brains are still developing.

These are some of the questions being tackled by Dr Sarah Knight, Dr Elisha Josev and colleagues from the Murdoch Children's Research Institute in Melbourne, Australia. ME Research UK awarded funding to the group to look at brain function in adolescents with ME/CFS, and the first results from the study were recently published in the journal, *Brain Imaging and Behavior*.

"Patients may have lower cognitive resources to draw on when mental effort is required"

The researchers aimed to look at the impact of mental effort on the cognitive function of adolescents with ME/CFS, as well as changes in functional connectivity in the brain.

Simply put, functional connectivity describes the links that exist between different regions of the brain, and which allow information to be processed. Activity occurring in two regions of the brain at the same time suggests a connection between those regions – either a direct pathway or an indirect cause-and-effect. For example, one specific connectivity network may indicate the processing of visual stimuli.

Mental exertion tests

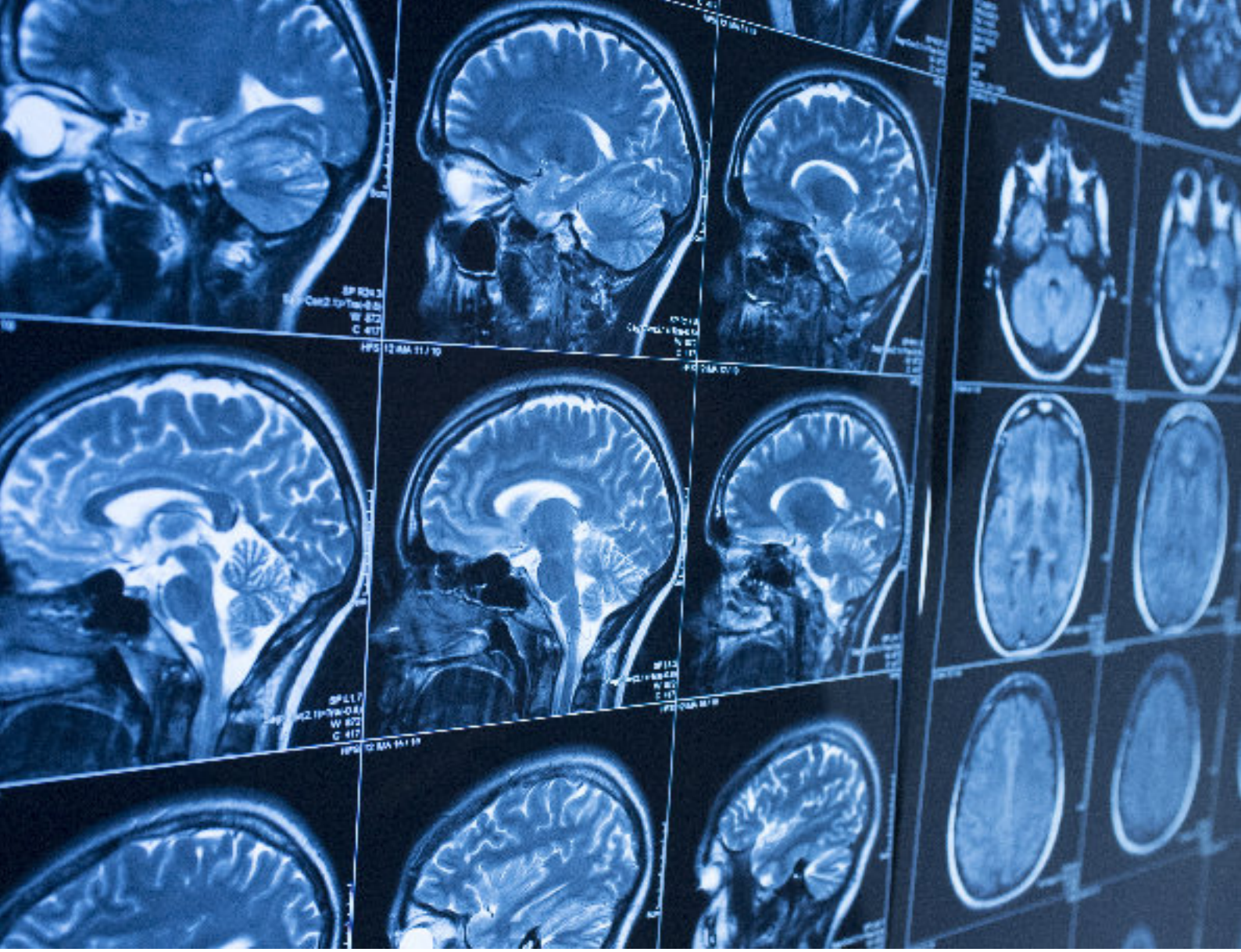
Forty-eight adolescents – including 25 with ME/CFS (defined using the Canadian criteria) and 23 healthy control subjects – were asked to undergo a 30-minute period of mental exertion, which included a number of tests of things such as literacy, mathematics and general intellectual ability.

Various aspects of cognitive function were measured before and after this exertion, and magnetic resonance imaging (MRI) was used to acquire images of the brain which were analysed to determine the presence of functional connectivity networks.

Levels of fatigue were also assessed in all participants.

Both before and after the period of mental exertion, the adolescents with ME/CFS performed worse than the healthy controls on the tests of cognitive function – including measures of processing speed (time taken to do a mental task), sustained attention (ability to focus on an activity), working memory (temporary storage of information) and visual new learning. They also had a higher level of fatigue.

However, the impact of mental exertion on cognitive function and fatigue was similar in ME/CFS patients and control



subjects. Fatigue increased, and processing speed and sustained attention decreased after exertion, but to a similar extent in both groups.

Similarly, functional connectivity decreased following mental exertion in the adolescents with ME/CFS and in the healthy control subjects, and this reduction was of a similar magnitude in both groups.

Lower resources

So what do these results mean? Mental exertion did reduce functional connectivity in the brains of these adolescents, but by a similar amount in both ME/CFS and control groups. So the energy expenditure caused by the exertion appears to be comparable in adolescents with and those without ME/CFS.

However, the adolescents with ME/CFS already had higher fatigue and reduced cognitive function, and the mental exertion resulted in even lower levels. The authors suggest that they will have had lower energy reserves and cognitive resources from which to draw on when mental exertion is required, so compounding their problems.

Although abnormalities in brain functional connectivity have been demonstrated in other chronic conditions such as fibromyalgia and chronic pain, and in some adults with ME/CFS, there is little indication from this study that this aspect of brain function will provide useful biomarkers for adolescents.

However, the Melbourne team is not stopping there. The MRI images collected provide a host of other information about brain function and structure, which the researchers have now started analysing. They have also been following up this group of adolescents over a longer period of time, and we look forward to seeing what's uncovered.

Senses working overtime

Oxford researchers are investigating **sensory processing and its association with brain function** in ME/CFS

Our senses are constantly being bombarded with information from our surroundings – the sights, sounds, sensations and smells around us, as well as the tastes in our mouths.

The brain has to work hard to process all this information simultaneously, and filter out what's irrelevant so we can concentrate on what's important at any given moment. But this ability can be impaired in people with certain clinical conditions, leading to a disabling hypersensitivity to the stimuli around them.

Hypersensitivity

The resulting physical and mental overload can lead to poor coordination, dizziness, clumsiness, numbness, tingling and nausea, and may affect individuals' ability to take in information and make decisions.

Dr Sanjay Kumar, Dr Farzaneh Yazdani and colleagues at Oxford Brookes University have previously looked at this phenomenon in people with post-concussion syndrome following head injury. And we recently awarded funding to the team to investigate the problem in ME/CFS.

Although hypersensitivity is not considered a primary factor in the diagnosis of ME/CFS, it is a common finding in people with the condition. This was borne out when the team met with people from a local ME support group, many of whom identified

Dr Sanjay Kumar

Dr Farzaneh Yazdani

with the issue and said that it interfered with their daily life.

This prompted a series of investigations to understand the nature and impact of the sensory problems experienced by people with ME/CFS, and to determine whether they are associated with any functional or electrical changes in the brain.

Sensory processing

The team aims to recruit 40 patients with ME/CFS and 40 healthy control subjects, and will begin their investigations by using a self-report questionnaire to assess patterns of sensory processing and how they affect functional performance.

The participants will then complete a series of neuropsychological tests (see Box) to investigate a range of cognitive processes, followed by some simple computer-based tasks, while the electrical activity of the brain is measured non-invasively using electroencephalography.

The investigators' hope is that the results of this preliminary work will help in our understanding of the brain mechanisms that underlie the abnormal sensory experiences of people with ME/CFS, and also lead to the development of interventions to help manage these problems.

Neuropsychological tests

Rapid Visual Information Processing
Ability to sustain attention. Participants press a button when a specified sequence is detected in a stream of random numbers.

Delayed Matching to Sample
Visual recognition and short-term visual memory. Participants match a pattern to one of four options shown below.

Stop Signal Task
Impulse control. Participants respond to an on-screen task but must not respond if they also hear a beep.

NO problem?

New study looking at **nitric oxide production in ME/CFS**

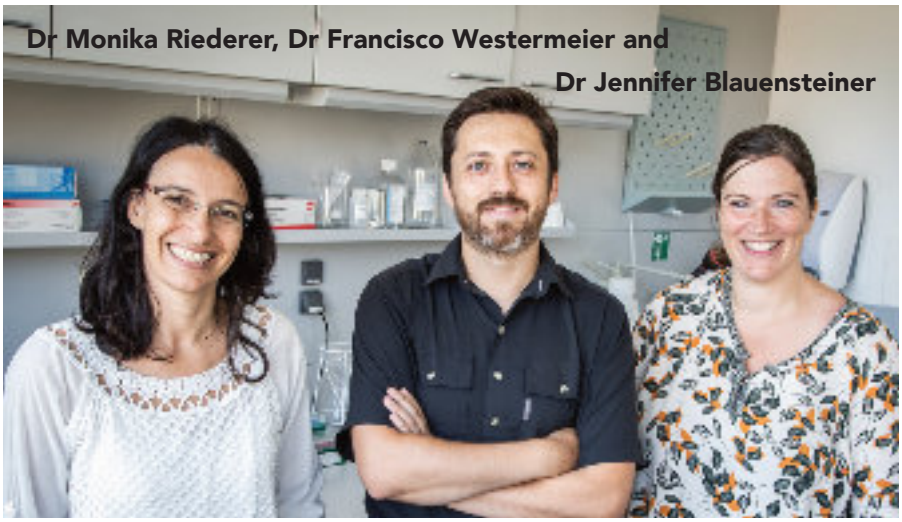
The immune system is a hot topic in ME research, with many studies published or currently ongoing.

And we have recently awarded funding to Dr Francisco Westermeier and colleagues at the Institute of Biomedicl Science, FH Joanneum University of Applied Sciences in Graz, Austria to explore immune abnormalities in ME/CFS.

One consequence of an activated immune system is inflammation. This is part of the body's defence mechanism – increased blood flow to an injured area, and an influx of immune cells into the tissue to repair damage.

But sometimes inflammation can persist for longer than required, or be triggered unnecessarily, itself causing damage.

Inflammation has been implicated in a number of cardiovascular conditions, specifically its impact on the function of the endothelium. This is a layer of cells lining every blood vessel involved in controlling their opening and closing, and hence the amount of blood flowing.



Dr Monika Riederer, Dr Francisco Westermeier and Dr Jennifer Blauensteiner

Some of the first research funded by us was conducted 20 years ago by a team at the University of Dundee looking at endothelial function in ME/CFS.

One of the ways the endothelium controls blood flow is through the release of a chemical called nitric oxide (NO). But NO is a double-edged sword – while it is essential in normal endothelial function, too much can be damaging and lead to prolonged inflammation.

Dr Westermeier is exploring this complicated relationship in more detail by looking at whether the cellular mechanisms that control NO production are altered in ME/CFS.

Using blood samples obtained from the UK ME/CFS Biobank, he will assess levels of NO and the proteins involved in its production. He will also investigate whether this is altered in endothelial cells exposed to ME/CFS blood samples.

The researchers hope their findings will throw new light onto the role of these complex mechanisms in ME/CFS, and possibly identify new biomarkers.

Dr Westermeier says that ME/CFS is "still poorly recognised in Austria, in part due to the lack of funding and research". He hopes this project will also help raise awareness of the condition in his country.

Research bites

Our round-up of recent research from around the world

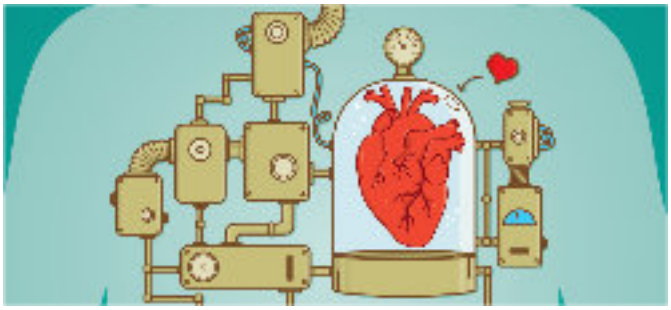
Psoriasis and 'CFS' risk

Tsai et al., Journal of Translational Medicine, 2019

Psoriasis is a skin condition caused by an increased production of skin cells. It is thought to result from abnormalities in the immune system, and is characterised by systemic inflammation. There is evidence to suggest that patients with psoriasis are more likely to experience fatigue, and a recent study from Taiwan looked at whether psoriasis is associated with an increased risk of developing 'CFS'.

The investigators identified 2,616 patients diagnosed with psoriasis between 2004 and 2008, as well as 10,464 individuals without the condition. They then looked at how many people in each group were subsequently diagnosed with chronic fatigue syndrome (as defined using 1994 Fukuda criteria) up until the end of 2011. After adjusting for differences in sex, age and other conditions, the researchers found that a diagnosis of 'CFS' during the follow-up period was nearly one-and-a-half times more likely among the patients with psoriasis than in those without the condition. This association was more marked in men and in older individuals, and was reduced after treatment with phototherapy or immune medications.

A diagnosis of 'CFS' is likely to encompass a range of diverse illnesses, including but not limited to what we would define as ME. Nevertheless, this study does provide more evidence that an altered immune system is involved in the pathology of ME.



Chronotropic intolerance

Davenport et al., Frontiers in Pediatrics, 2019

Our heart rate normally rises when we exercise, in order to increase the amount of blood pumped by the heart. However, a new review from the University of the Pacific, in California, shows how this response is impaired in many people with ME/CFS. The phenomenon is known as chronotropic intolerance, and potentially provides further evidence of autonomic dysfunction in the illness (as demonstrated in work by Prof. Newton in Newcastle). The authors suggest their findings also raise questions about the use of pacing to manage ME/CFS.

Key research findings

Komaroff, JAMA, 2019

Writing in the prestigious journal, *JAMA*, Anthony Komaroff from Harvard Medical School provides a helpfully succinct overview of key research findings in ME/CFS, covering the nervous system, metabolism and immunology. He then proposes how these findings might be tied together in a unifying model of the illness, where responses to injury or potential injury have been activated but cannot be turned off. Dr Komaroff also suggests the fascinating idea that ME/CFS may be a kind of hibernation state, intended to preserve energy in response to a threat.

Marker of inflammation

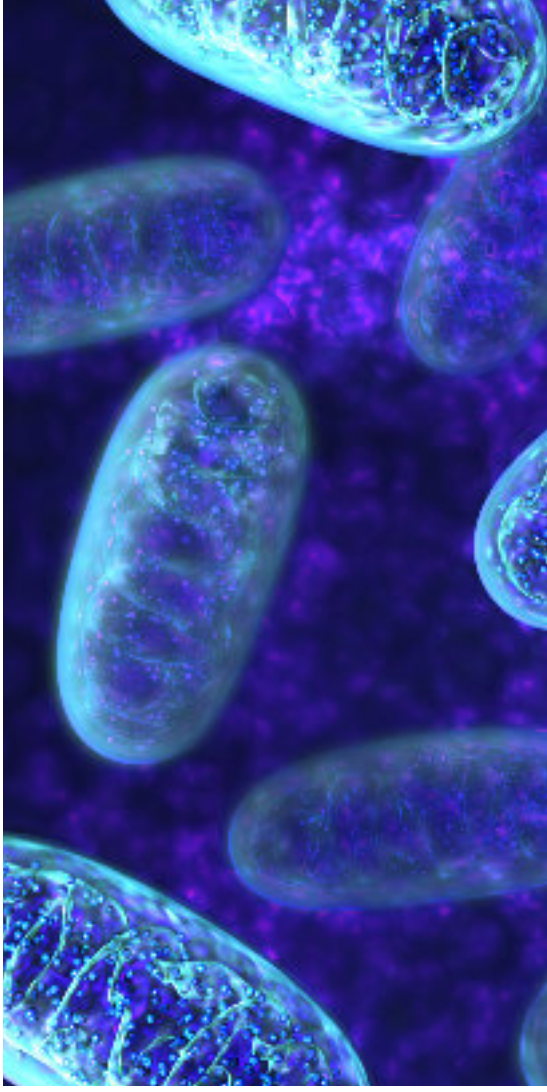
Groven et al., Brain, Behavior, and Immunity, 2019

Further evidence of inflammation in ME/CFS comes from a Norwegian study in which levels of high-sensitivity C-reactive protein (hsCRP) were measured in 49 women with 'CFS' (Fukuda criteria), 57 with fibromyalgia and 54 healthy control subjects. After adjusting for age, smoking and body mass index, hsCRP levels were significantly higher in both patient groups compared with the controls, and there was no difference between the 'CFS' and fibromyalgia cohorts. These results agree with the findings of two previous ME Research UK-funded studies conducted in male and female patients.

Impact of endometriosis

Boneva et al., Frontiers in Pediatrics, 2019

Endometriosis – the spread of endometrial tissue outside the uterus – is relatively common among women with ME/CFS. In a recent study from Atlanta, Georgia, 36.1% of women with 'CFS' had the condition. These individuals were more likely to have chronic pelvic pain, earlier menopause and a previous hysterectomy, and they also had more CFS-related symptoms. Endometriosis did not have any impact on functioning, fatigue or inflammatory markers, but most participants were postmenopausal, and a better indication might come from studying a larger group of younger women.



Mitochondrial complex activity

Tomas et al., PeerJ, 2019

The mitochondria are the power plants of the body, generating the energy needed to support life. Substantial evidence suggests that mitochondrial function is abnormal in people with ME/CFS, but what part of the energy production pathway is faulty? In a study from Newcastle University, Cara Tomas and colleagues looked at the activity of protein complexes within the mitochondria. These complexes are involved in the generation of a molecule called ATP, which is used to transport energy within the cell. Using a technique called extracellular flux analysis, the team found no differences in mitochondrial complex activity or respiratory activity between cells from patients and those from controls, and this was true in both white blood cells and skeletal muscle cells. These results suggest that the abnormality in energy production in ME/CFS lies upstream of this respiratory chain, and this agrees with previous findings from other groups.

Post-exertional malaise

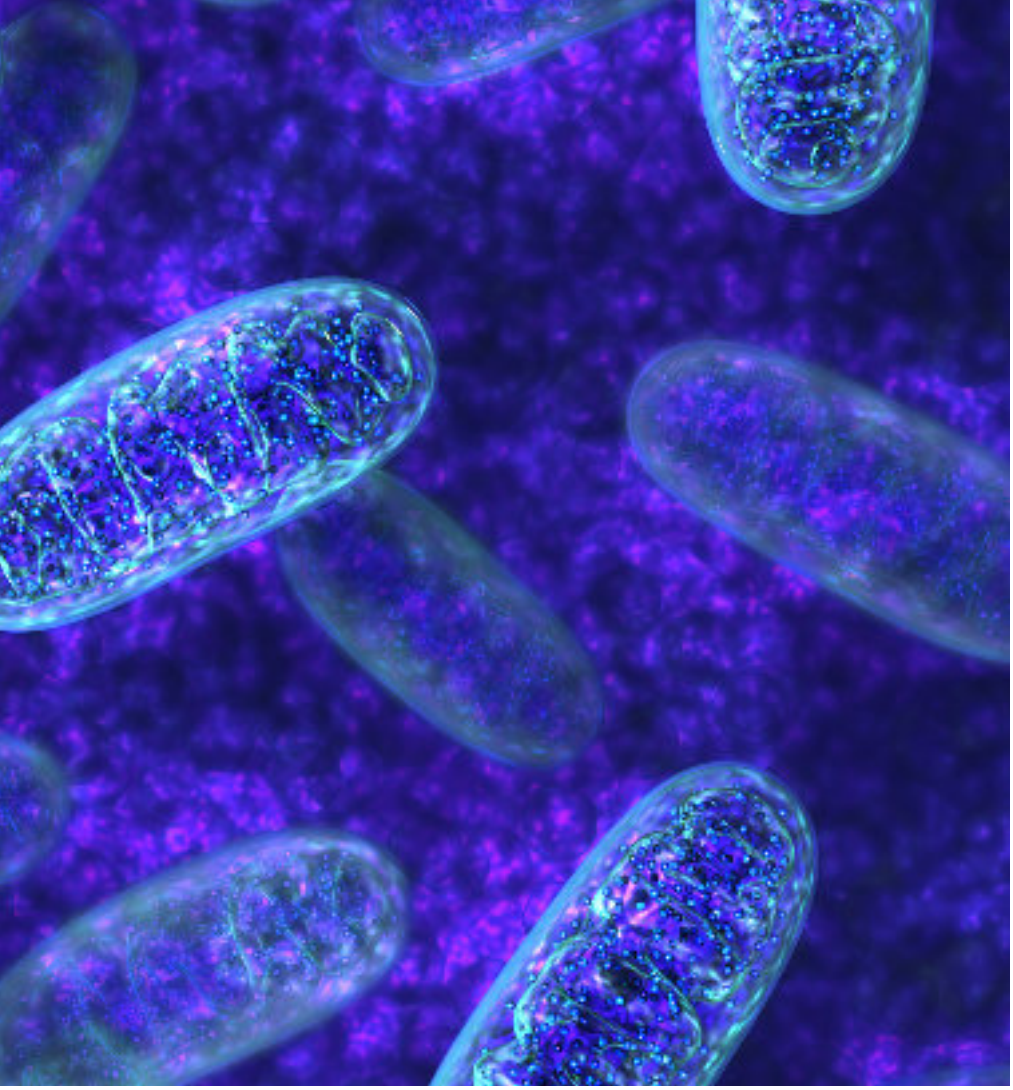
Holtzman et al., Diagnostics, 2019

Post-exertional malaise (PEM) – the worsening of symptoms following physical effort – is a major problem for many people with ME/CFS. In this paper from Chicago, the authors describe their attempts – in collaboration with the patient community – to develop a valid, comprehensive tool to assess PEM, capturing several aspects that have not been assessed by previous tools. Their questionnaire was shared with patient groups, and revised several times in response to the comments received. Most participants felt that the survey accurately or very accurately captured their experiences of PEM.

Genetic predisposition

Perez et al., Frontiers in Pediatrics, 2019

A genome-wide analysis of 383 patients with ME/CFS was recently completed by researchers in Fort Lauderdale, Florida. They identified 5,693 single-nucleotide polymorphisms (SNPs) that were at least twice as frequent in their ME/CFS cohort as in a reference cohort, or at least twice as frequent in the reference cohort. SNPs are common genetic variations which can act as biological markers of disease, or predict susceptibility. Most of these SNPs identified in these patients were in genes related to immune system, hormone, metabolic and extracellular matrix function.



"Abnormality in energy production lies upstream of respiratory chain"

Activin B as a biomarker?

Lidbury et al., Diagnostics, 2019

Activin B is a protein with a number of roles related to the immune system and inflammation, and pilot work from a group at the Australian National University identified it as a potential biomarker for ME/CFS. They have now repeated the research in a larger patient cohort, reporting decreased levels of activin B in patients compared with controls, which is the opposite of their previous findings. Adding activin B to a panel of other pathology markers improved the prediction of mild to moderate ME/CFS. The authors suggest that larger, multicentre studies of activin B are now needed.

Hyperosmotic stress test

Esfandyarpour et al., PNAS, 2019

The search for a biomarker for ME/CFS continues with a study from Stanford University, California. To mimic the onset of post-exertional malaise, nanoelectronics were used to measure changes in the electrical properties of blood samples containing immune cells that had been stressed by the introduction of salt. The impedance of the samples increased in 20 patients with moderate to severe ME/CFS, but was unchanged in 20 control subjects. The investigators do not yet know what these changes represent, but they plan to confirm the findings in a larger group of patients.

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

We were proud to be supported by the Celtic Wiseman Perpetual once again this year. These cycle routes were originally established in Cornwall in 2010 by friends of Martin Wiseman who has been bed-bound with ME since 2008. This year saw the inaugural Celtic Wiseman (Cyrmu) ride around West Wales, a gruelling 116-km route starting from Aberporth. The team comprised four of Martin's friends – Richard Davies, Aled Edwards, Paul Magee and James Partington – who completed the ride on 26 May, with a dreadful start but a brighter afternoon. PTWNGI? Play To Win & Never Give In!

Spoonie survival kits

These "little bags of happiness" contain items to help people with long-term conditions to smile and remind them they are not alone. SSK – which creates and sells these kits from their Etsy shop – selected us to be their featured charity from April to June, during which time 50% of all profits was donated to ME Research UK. We're very grateful to them.

ME awareness week

Thanks to Jo O'Driscoll, the 72-foot-high Smeaton's Tower at Plymouth was bathed in blue to raise awareness of ME. The lighthouse was originally built on the Eddystone reef in 1759, but was dismantled in the early 1880s and moved stone by stone to its current resting place.

01

02

03

01 The **Peaky Climbers** just about to set off on their challenge

02 Smeaton's Tower is all lit up

03 An ecstatic **James Everett** crosses the finishing line

Peaky Climbers

At the beginning of July, Connor Frampton, Claire McCann, Lauren Knowles, Adam Harding, Andy Wood and Katie Wood took part in the 3 Peak Challenge in aid of ME Research UK. Their awe-inspiring challenge was to get to and climb three peaks in 24 hours, namely Ben Nevis, Scafell Pike and Snowdon. After much preparation in the windy Brecon Beacons, the team completed their challenge in July, and raised a magnificent total for ME Research UK. Thank you so much!

London Marathon 2019

Many thanks and congratulations to James Everett who completed the Virgin Money London Marathon on 28 April, in an amazing time of 4 hours 14 minutes, and raised a wonderful total for ME Research UK. As James says, "With a number of friends and family having previously suffered, or currently suffering from ME/CFS, I'm raising funds for scientific research into this commonly misunderstood condition." Thank you to James, and of course his many generous supporters.

AmazonSmile

One easy way to support ME Research UK is by using AmazonSmile every time you shop at the online store. Go to smile.amazon.co.uk and select us as your chosen charity. Amazon will donate 0.5% of the purchase price, at no extra cost to you.

04 Nick Pearson in training for his Polish Ironman challenge

04

Ironman Gydnia

The training was intense for Nick Pearson as he prepared for the Ironman 70.3 triathlon in Gydnia, Poland, all in support of the work of ME Research UK. He has notched up thousands of kilometres in training since January, but it all paid off when he completed the tough course on 11th August. Nick's feat included a 1,900-km swim, 90-km bike ride and half-marathon run. Many thanks to Nicholas for his superhuman effort, and to his employers, GKN Aerospace, who pledged to match 20% of the total raised.

Wayne's Wirral Walk

Hats off to Wayne Roach who completed the 2019 Wirral Coastal Walk in support of ME Research UK – and in My Little Pony pyjamas! "ME is a condition I know all too well. My wife Kelly was diagnosed with it shortly after giving birth to our twins. I have seen the dramatic changes it has made to her. ME research is so poorly funded and affects far too many people. If I don't raise a single penny, I just want to raise awareness along with telling the world how lucky I am to be married to an ME sufferer; she is amazing."

New Year's resolutions

At New Year, people often think about how to support their favourite charity, and it's not too early to start planning how to help us.

You could set up a regular payment using the form opposite, sign up for a running or walking event, have a clear-out and sell unwanted items or presents on eBay, or plan a party or social event.

There's skydiving, baking, cycling, haircutting, tattooing – no end of great ideas to raise awareness of ME and funds for ME Research UK. Use the stories in *Breakthrough* for inspiration, and our website has a wealth of ideas as well as guidance on how to organise your event.

Have fun, and don't forget to tell us all about it.

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**

Name of account holder(s)

Address

Postcode

Telephone number

Name of Bank or Building Society

Branch address

Branch postcode

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

Debit amount (£)

Payment date each month

Date of first payment

Pay to: Clydesdale Bank, 158/162 High St, Perth, PH1 5PQ, UK, Account: ME Research UK, a/c no: 50419466, Branch code: 82-67-09

☐ **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